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Telehealth Services for Children With Autism Spectrum Disorders in Rural Areas of the Kingdom of Saudi Arabia: Overview and Recommendations

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Abstract

Autism spectrum disorders (ASD) are the most-prevalent neurodevelopmental disorders. However, each child diagnosed with ASD presents with a unique range of behavioral and communication problems and issues with social skills. Many studies have highlighted the importance of early interventions for children with ASD to improve their skills and provide their families with the necessary support. However, in the Kingdom of Saudi Arabia (KSA), the earliest that a child with ASD in the major cities receives an intervention is at the age of 4 years, owing to limited services and a lack of awareness of the importance and benefits of early interventions. Families who live in rural areas of KSA arguably have a greater need for these services, as they have to travel to cities such as Riyadh for help. The use of telehealth services may be effective for ASD intervention among children living in rural areas, since such services use technology to provide consultations, interventions, diagnosis, training, and education. Research indicates that telehealth services are as valuable as traditional face-to-face treatment, allow families to obtain support from their homes, and help them improve their quality of life. This review will discuss the application of telehealth services to support families in rural areas of KSA who are dealing with issues of ASD, considering the cultural and religious contexts. In addition, it will examine ways in which technology can be employed to suit KSA's culture and needs.

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autism spectrum disorders; intervention; Saudi Arabia; telehealth

Introduction

Autism Spectrum Disorder (ASD) is the most-widespread developmental disability: Its global prevalence has dramatically increased from a rate of 1 per 10,000 people in the 1980s to 1 per 68 people in 2016 [1]. However, in the Kingdom of Saudi Arabia (KSA), there are no data about the number of cases of ASD, although it is estimated to be over 167,000 in a population of over 28 million people [2]. In addition, the services available for children with ASD in the cities do not meet the demand; as a result, some families are forced to travel to neighboring countries such as Jordan or overseas to countries such as the United States for these services [2]. Research worldwide aims to continually develop ways to improve interventions in order to ensure better lives for children with ASD and their families [3]; however, KSA is significantly lagging in relevant developments [4], because the methods developed in the West are not usually culturally suitable for KSA, particularly with regard to prescribed gender roles [1]. However, one method that might be effective is telehealth services. From this view point, we will review evidence from countries outside KSA that prove the effectiveness of telehealth in providing services to children with ASD. In addition, we will discuss the potential applications of this method in the Saudi context, and the challenges it may pose, in particular, due to cultural specificities. Further, we will provide recommendations to overcome these barriers. We performed a narrative literature review, as this is a useful method to develop recommendations for clinical practice [5]. Relevant literature was identified through an electronic keyword search of four databases (PubMed, Web of Science, Cumulative Index to Nursing & Allied Health Literature, and Scopus) using the search terms "telehealth," "family-centered approach" or "technology," in combination with the term "autism" (using the AND Boolean term), and dated up to April 2017. Broad search terms were used for their relevance to the research question and to reduce selection bias. However, the search was confined to peer-reviewed papers, as the literature review was not systematic; additionally, unpublished and grey literature was not considered appropriate for clinical practice, due to its low standard of evidence.

Telehealth Services for Children with Autism Spectrum Disorders

The most evidence-based intervention for children with autism is early behavior intervention [6], which has several advantages including its ability to be delivered by anyone with training, not only practitioners with advance degrees (such as clinical psychologists or therapists). Therefore, in early behavior interventions, even caregivers are practitioners, provided they have received training. In addition, the use of a family-centered approach to educate and support caregivers of children with ASD has been found to improve outcomes for children [7]. In this approach, the caregivers' needs are taken into account, and caregivers are trained to interact with children with ASD, without therapists assuming the knowledge of caregivers [8]. Russa and colleagues [9] concluded that ASD interventions are interdependent on caregivers and that active engagement of caregivers is key to positive outcomes. However, delivery of early behavior interventions and family-centered services face-to-face poses many barriers such as the scarcity of trained therapists, limited resources and services, low socioeconomic status of many families, lengthy waiting lists, and practical issues arising from the fact that these limited services are only available in major cities [10]. Therefore, it is important to determine ways to help caregivers adapt new methods to deliver interventions for ASD [10]. Due to the significant increase in the use of the computer and Internet in everyday life, telehealth services, which use technology to provide services from a distance to families with a child with ASD, could be an alternative and effective method of providing support [10]. This method has many advantages. First, the family can interact with an instructor directly via video, which potentially provides access to a greater range of expert therapists. Second, by providing caregivers with an opportunity to play an active role in the child's development, telehealth technology can empower caregivers and accelerate the diagnostic process [10,11].

Telehealth consists of a range of computerized software applications such as video conferencing, digital versatile discs, three-dimensional interactive programs, mobile phone apps, and telephone- and web-based tutorials [12]. Studies of telehealth-based parent training showed that the caregivers found the training programs convenient, practical, appropriate, and helpful for increasing their knowledge about evidence-based intervention methods [13-15]. In addition, studies reported positive changes in children's outcomes [3,10,11,16]. For instance, a study of North American families with children aged < 48 months who had ASD revealed that teaching parents the Early Start Denver Model intervention through videoconferencing and a web tutorial increased the rates of vocalization and joint attention initiation in children [3]. Similarly, a study of children aged 24-72 months with ASD in North America found that teaching parents an imitation intervention through remote coaching and self-directed online study increased spontaneous imitation in the children [10]. However, most studies included a small to very-small sample size; the only study with a reasonable sample size [13] did not measure children's outcomes and implemented the training with caregivers and professionals who worked with children with ASD (eg, teacher assistants). Another limitation is that the studies mostly included college-educated participants, although the principles of early behavior intervention state that it can be implemented even if one does not have an advance degree [13]. This limitation will be further discussed in the context of KSA.

Barriers and Challenges in Adopting Saudi Telehealth Services for Children with Autism Spectrum Disorders

In KSA, families of children with ASD, particularly those living in rural areas, encounter many difficulties when seeking support [4]. As mentioned earlier, the number of children with ASD is increasing, but services are only available in major cities. In addition, due to the limited resources, waiting times for appointments or family-centered approach sessions can take 8-12 weeks [17]. Moreover, several aspects, including the costs of travel and the service itself as well as the need to manage receipt of support for their child while maintaining jobs and fulfilling other responsibilities, lead to a significant strain on families living in rural areas of KSA [2,17,18]. For such families, telehealth could address many such issues and provide additional support to existing services. Telehealth services could be used as a tool for teaching strategies to improve the outcomes of children with ASD and their families [17,19]. However, the cultural context, beliefs, educational levels, and socioeconomic status of the KSA population need to be considered when selecting appropriate methods of intervention [18]. Furthermore, because telehealth services employ technology in a new way, research is required to identify a reliable, evidence-based telehealth framework and intervention program in order to deliver services from a distance in KSA.

The first issue is that in KSA culture, women assume the role of a homemaker and carer, whereas men provide for and protect the family, leaving the mothers with almost complete responsibility of caring for the children [20]. In addition, KSA culture dictates that men and women should always be separated (eg, in education, banking, and health), women should cover their faces in front of men, and some women are not allowed to have their picture taken [20]. These rules make communication between genders a sensitive issue [21]. In fact, face-to-face contact, including online communication, between men and women is prohibited by culture [21]. Therefore, in some cases, interventions or interviews with mothers of children with ASD are not allowed to be conducted by men without the presence of the mother's relatives [22]. This reduces opportunities for teleconference or video-conference for face-to-face sessions between the therapist and the child's mother, which could otherwise help the therapist provide recommendations, answer questions, and design an intervention strategy while observing the child through a camera in the child's home [23].

The second obstacle to the use of technology to provide assistance to families affected by ASD is the prerequisite that the family have a computer or mobile phone that can be used to access the internet, a high-speed internet connection, and information technology literacy [19]. Although 40% of KSA families living in rural areas are living below the breadline [24], by 2012, 95% of Saudi individuals had a mobile phone and mobile internet penetration was 70% [25]. As such, it is unlikely that parents of children with ASD do not have access to the internet, or at least a mobile phone, in some form.

The use of telehealth programs to assist families with a child with ASD requires training [19]. Thus far, studies that examined the effectiveness of telehealth in the context of ASD mostly recruited educated participants. However, KSA has overall poor education levels [18]. In rural areas, many mothers of children with ASD do not have a degree and have often not attended high school [18]; some of them are illiterate, which makes the use of technology extremely difficult [2,18,22]. In addition, the Saudi government does not provide sufficient education on the use of technology. Therefore, institutions such as public schools in rural areas are often unaware of the latest advances in technology [24].

The third problem with implementing a telehealth service in KSA is the need for Saudi mothers, as the principal carers, to talk to female, rather than male, therapists [26]. Although the health system allows a mix of genders in KSA, this is a male-dominated field with a low number of Saudi women [20,27]. Thus, the majority of female professionals in the KSA healthcare system are foreign workers, which often results in problems with the delivery of information because a translator, who is usually a non-expert, is needed [20,27]. In addition, many online applications are not in Arabic, and therefore, a team is required to translate the applications into Arabic. Furthermore, Saudi expertise in technology is limited [27].

Finally, the use of telehealth services requires caregivers to act as the child's ASD therapist, managing new strategies for care and using different technological methods of intervention from professionals [10]. However, Saudi families, especially mothers, historically have profound trust in healthcare professionals, which might deter them from assuming such an influential role in their child's intervention without a healthcare team [28].

In summary, introduction of technology to support families living with ASD in rural areas has many advantages, including flexibility. However, KSA is a traditional country where Islamic teachings and Arabic cultural values are strictly followed; therefore, such telehealth services need to be selected and implemented carefully. In addition, cultural factors such as the need to hire both male and female Arabic-speaking educators, gender roles, and educational levels need to be considered.

Recommendations for Best Practice

Since telehealth services have recently been introduced in KSA, many of the abovementioned barriers could prove detrimental to the success of this service. However, there is an evident need to help families with children with ASD who are living in rural areas [4]. The world revolves around technology, which enhances social interaction; facilitates knowledge sharing among health professionals, individuals with ASD, and the whole community; and will lead to positive change in the health sector (eg, through treatment plans) [28]. For example, the use of mobile internet technology such as WhatsApp has shown promising results in reducing stress through interventions in Saudi parents of children with ASD [29].

Considering the recent evidence, the government and health minister need to implement these telehealth services to assist families affected by ASD, through the use of technology, engaging both genders in the use of computers and up-to-date software. In addition, an increase in socialization between genders and the fact that this change might benefit children with ASD could positively affect the development of children and families by improving access to quality medical and behavioral services in the healthcare system [4]. However, occasionally, the distribution of physical training materials (eg, printed manuals) may be required to educate people in rural areas without internet access. Nonetheless, not all rural regions of KSA lack access to the internet, and as highlighted above, mobile phone ownership is now widespread, with extensive mobile internet penetration [25]; it would therefore be valuable to consider the use of telehealth services for such regions.

Many Saudi caregivers reported that their children were diagnosed with autism at the age of 7 years, because the hospitals in their area were not trained sufficiently to diagnose autism [22]. The caregivers had to refer the children to big cities for a diagnosis, which took months because of the limited number of professionals with the ability to diagnose the disorder. Evidence indicates that early intervention improves children's outcomes, and a delay in diagnosis can lead to a delay in early intervention services [28,30]. In this regard, the use of the Naturalistic Observation Diagnostic Assessment (NODA) SmartCapture, a mobile phone app for caregivers to record video evidence of a child's behavior in their natural environment (eg, the home), could help diagnosticians confirm the diagnostic assessment of ASD [11]. Using NODA, caregivers place the child in specific social scenarios to ensure that the recorded videos provide professionals with the necessary elements for a diagnosis [31]. The scenarios were designed with reference to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition, criteria [32]. Preliminary research showed 91% agreement between diagnoses made using NODA and those made face-to-face previously by another professional [11].

The NODA method presents specific advantages for rural populations. First, families do not need to purchase relatively expensive equipment and pay for travel expenses, which makes the method cost effective and consequently, much more attractive than face-to-face visits [10,11]. In addition, families of children with ASD, who may dislike changes to their routine and social context, do not need to travel to large, unfamiliar cities, which evidently reduces stress [10]. Moreover, online assessment through videos would be more ecological, as the child would be in his or her natural environment. Although online assessments may lack reliability, Smith et al. [33]

reported similar results between online and face-to-face clinician assessments of ASD in a prospective study of 50 families (88.2% agreement). Furthermore, 95% caregivers reported that NODA SmartCapture was easy to use and they were able to record videos in their homes successfully [34]. Therefore, NODA SmartCapture could improve the efficiency of the diagnostic process for ASD in KSA.

The uneven internet access in KSA could hamper the effectiveness of NODA in rural areas. Professionals should therefore consider the use of telephone services for diagnoses, as a standby option [16], as 95% of the population owns mobile phones [25]. Professionals could administer the Autism Diagnostic Interview-Revised (ADI-R) via the telephone [35]. The ADI-R is the gold standard test for the diagnosis of ASD. Research in diagnoses made by ADI-R showed that there is no significant difference between face-to-face interviews and those performed over the phone [35]. Once an ASD diagnosis has been established, we recommend that the family visit a major city for further assessment (eg, intellectual assessment), as there is limited evidence that these assessments can be performed via telehealth for ASD in young adults [36]. Although it is inconvenient that people receiving a diagnosis remotely need to travel to a major city for an intellectual assessment, this method will minimize the number and cost of trips and can therefore reduce the average age at which people in rural areas are diagnosed, thereby facilitating early interventions. Once a full assessment is conducted, the aim is to provide further support for interventions through telehealth (and occasionally printed materials), which will further reduce the number for trips needed. Moreover, remote consultations could minimize the burden on hospitals in major cities by identifying people whose behaviors are not symptomatic of ASD and who therefore do not need in-person consultation.

Second, web-based learning could be of immense help to the families of children with ASD after diagnosis, as it could potentially include video tutorials that highlight specific ASD behaviors and advise caregivers on the correct use of intervention strategies [37]. In KSA, the use of web-based learning is theoretically valuable and flexible, as it can be adapted to suit the cultural context of families of children with ASD [37]. In addition, although male therapists in KSA cannot train female caregivers face-to-face about behaviors of children with ASD, it would be acceptable for women to watch learning videos made by male therapists, as this does not represent direct contact. This is an additional advantage of telehealth in the Saudi context: The use of learning videos will allow therapists to train a wider population outside the major cities and reduce reliance on female trainers, which is necessary for delivering face-to-face training to female caregivers. Therefore, for Saudi female caregivers who cannot read or understand medical terms, such videos would be immensely useful. The website could also have a forum either using email or a method similar to email, so that caregivers can send and receive voice or text messages to their therapist, who could then provide instantaneous advice and support [3]. Since the Saudi culture is strict about communication between genders, the forums should be moderated by female staff through whom communication between female caregivers and male therapists could occur.

Another method would be to develop a website that provides caregivers and the general public with resources such as information on autism symptoms, educational brochures, early interventions programs, strategies for dealing with issues at home, community activities, and local events [3]. In addition, it should allow caregivers to post anonymous conversational topics, tips, and progress updates about their child or any other information they may want to share [3]. In KSA, such a method could help resolve the separation issue between the genders, thereby helping them support each other, increasing awareness of other local families of children with ASD, and keeping them up-to-date on new interventions for ASD. This method would also help raise public awareness of ASD symptoms [22] and increase the probability of caregivers seeking treatment early, even in rural areas. As mentioned earlier, online training for families of children with ASD were as effective as face-to-face workshops [38].

Telehealth services could also benefit health professionals. Alqahtani [22] stated that many ASD therapists in KSA are not trained for the latest intervention strategies; as such, web-based learning could help update them on the latest research and intervention techniques [16]. For example, a preliminary study by Vismara et al. [38], including 10 therapists, showed that training therapists to use the Early Start Denver Model for ASD via telehealth was particularly effective, and Hamad et al. [13] found that a large sample of training therapists could significantly improve knowledge about early behavior intervention after e-learning.

Finally, a few different interventions have been tested through telehealth in recent years [39]. In most studies, the outcomes were positive [37,39], suggesting that telehealth could be applied to most interventions in practice. Providing caregivers with online coaching is conducive to achieving optimal outcomes. For instance, Ingersoll and Berger [40] found that parents of young children (aged 27-73 months) were more likely to engage in a social communication intervention (ImPACT Online) if, in addition to completing online lessons, they participated in 30-minute videoconferences with therapists twice per week, as compared to parents who only completed the online lessons. Notably, engagement in the group receiving only online lessons was high, and the lessons included a range of media such as slideshows, videos, quizzes, and reflective questions. Similarly, Pickard et al. [41] observed that in comparison to parents who completed a self-directed online study, parents who received additional online coaching via Skype were more likely to report improvements in communication in children aged 19-73 months. Lindgren et al. [42] reported that delivery of functional communication training through telehealth in the caregiver’s home is as effective as that in a regional clinic and in-home therapy with respect to reducing problematic behaviors in children aged 21-48 months. However, home-based telehealth is the most affordable of these approaches. Collectively, these results suggest that online web-based lessons that use a range of media represent an effective and comparatively cost-effective method to improve outcomes in children with ASD and that their efficacy might be enhanced by online coaching. However, further research is needed to directly compare telehealth interventions in order to recommend the most-effective option;

this is even more important in light of publication bias, through which results less favorable than those of telehealth might not be published [39,43].

Conclusion

Although autism is becoming increasingly recognized as a disorder in KSA, there are limited services for autism in rural areas. Increased public awareness about the disorder is needed to meet the demand for adequate services, support, and research that are suitable to the Saudi culture. Although services and support can be found in major cities, this is not the case throughout the country. Alternative methods for assisting families dealing with ASD can be potentially identified through technology. However, the use of technology involves many obstacles due to KSA's culture and religion. Adapting the technology accordingly could make a significant difference to the families with children with ASD. Moreover, telehealth services could allow healthcare professionals in KSA to interact with caregivers in rural areas, providing consultations, behavioral interventions, and other support. Furthermore, such methods may lead to more acceptance use of technology in society, in general. However, for this progressive, yet effective, method of support to gain momentum in KSA, research on its implementation is urgently required.

Conflicts of Interest

None declared.

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Abbreviations

ADI-R: Autism Diagnostic Interview-Revised
ASD: Autism Spectrum Disorder
KSA: Kingdom of Saudi Arabia
NODA: Naturalistic Observation Diagnostic Assessment

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Original Paper

Engaging Men in Prenatal Health via eHealth: Findings From a National Survey

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Abstract

Background: Pregnancy outcomes in the United States rank among the worst of countries with a developed health care system. Although traditional prenatal health primarily focuses on women, promising findings have emerged in international research that suggest the potential of including men in prenatal health interventions in the United States. eHealth apps present a promising avenue to reach new and expectant fathers with crucial parenting knowledge and healthy, supportive behaviors.

Objective: The aim was to explore the perceived role of men in prenatal health, acceptability of eHealth to positively engage men during pregnancy, and participant-suggested ways of improving a prenatal health app designed for new and expectant fathers.

Methods: A nationally representative sample of adult males (N=962) was recruited through an online survey panel. A third-party market research and digital data collection agency managed the recruitment. The sample had a mean age of 30.2 (SD 6.3) years and included both fathers (413/962, 42.9%) and non-fathers (549/962, 57.1%). Nearly 12.0% (115/962) of participants had a partner who was pregnant at the time of the survey.

Results: Despite perceived barriers, such as time constraints, financial burdens, and an unclear role, men believe it is important to be involved in pregnancy health. The majority of participants (770/944, 81.6%) found the site to contain useful and interesting information. Most substantially, more than three-quarters (738/962, 76.7%) of the sample said they would share the site with others who would benefit from the information. Participants recommended the addition of interactive modules, such as a financial planning tool and videos, to make the site stronger.

Conclusions: We explored the use of targeted eHealth to introduce men to prenatal education. Results indicate men are favorable to this intervention. Additional refinement should include interactive tools to further engage men in this important issue. Reaching men at the prenatal phase is an early “teachable moment”—where new/expectant fathers are open to information on how to help their partners have a healthy pregnancy and promote the health of their unborn children. Findings will further inform best practices for engaging men in pregnancy, which is crucial for improving maternal and child health outcomes in the United States.

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KEYWORDS

health communication; fathering; expectant fathers; prenatal health

Introduction

Maternal and infant mortality rates in the United States rank among the worst of all high-income countries. The most recent vital statistics reports estimate 6.15 infant deaths per 1000 live births and 15.8 to 28.0 maternal deaths per 100,000 live births—with marked disparities in outcomes among different races/ethnicities [1,2]. It is estimated that 60,000 women each year also suffer severe pregnancy-related issues considered “near-miss” maternal mortality [2]. Improving these outcomes is a goal of the US Healthy People 2020 initiative as well as a target of the United Nations Sustainable Development Goals. Health care access and social support during pregnancy can reduce risks that are known to drive maternal and infant mortality and morbidity [2,3].

To combat burdensome pregnancy outcomes, public health interventions and social marketing campaigns have played a key part in disseminating important information [4-6]. These interventions have been beneficial in promoting prenatal visits to health care providers, reducing mother-to-child transmission of diseases, and increasing breastfeeding practices [4,7,8]. Despite the success of these interventions, they have typically left male partners outside of a defined role in prenatal health care [9-12].

The inclusion of men in pregnancy-related education programs has been shown to increase provider visits during pregnancy, reduce maternal-fetus HIV transmission, and bolster postpartum best practices such as breastfeeding [13]. Research also suggests that positive male involvement during pregnancy is directly associated with positive male engagement in the formative days of a child’s life. The effect of involving men in pregnancy-related decisions has been shown to open up communication between the partners and increase the father’s efficacy in caring for the child [14].

Even though international research indicates that including men in these initiatives can improve outcomes, pregnancy continues to be a domain where men feel “invisible” and “sidelined”—prompting calls for interventions that educate and engage men on prenatal health topics [5,9,10]. Due to multiple factors, such as negative attitudes of health providers and time constraints, men are left feeling generally unwelcome in the arena of prenatal health. Research has identified several perceived barriers to men being involved in pregnancy-related health issues. These include having to work, having no time, having an unclear role, cultural norms, and the expense of such programs [10,11,15]. Given these commonly cited obstacles, the potential of using electronic health (eHealth) to educate men and motivate them to be more involved in prenatal health is encouraging [11,15]. eHealth has the ability to reach difficult-to-reach audiences, such as men, and to target information that may resonate better than existing programs designed predominantly for women.

The purpose of this study was to confirm promising pilot results on the perceived role of men in prenatal health and the potential of eHealth to reach them with information to increase their involvement in prenatal health (eg, attending prenatal visits to health care providers) [11,15]. This national survey stands to contribute to the body of research on how to encourage men to be positively involved in pregnancy to promote better health outcomes in the United States.

Methods

Participants, Recruitment, and Procedures

After Institutional Review Board approval, 962 adult males aged 18 to 40 years participated in the nationally representative survey. Recruitment and surveying occurred from March to May 2016. Participants were recruited from enrolled members of an invite-only research panel conducted by a third-party research firm that specializes in digital data collection. The participants had to opt-in to the study if they met survey criteria, which required participants to be adult males (aged ≥18 years). There was no upper age limit. The participants earned online credits for their participation in applicable surveys. Consent language and study contact information was provided before participants continued to the survey. All participants had to select “I consent to the protocol of this study” before viewing the content of the survey. The IP addresses were used to identify potential duplicate entries from the same user. Participation took between 10 to 30 minutes, with 94.4% (908/962) of the participants finishing within that timeframe. Prior to analysis, 64 surveys were dropped from the study because they were either blank or partially completed in less than 90 seconds. These 64 are not included in the final N=962.

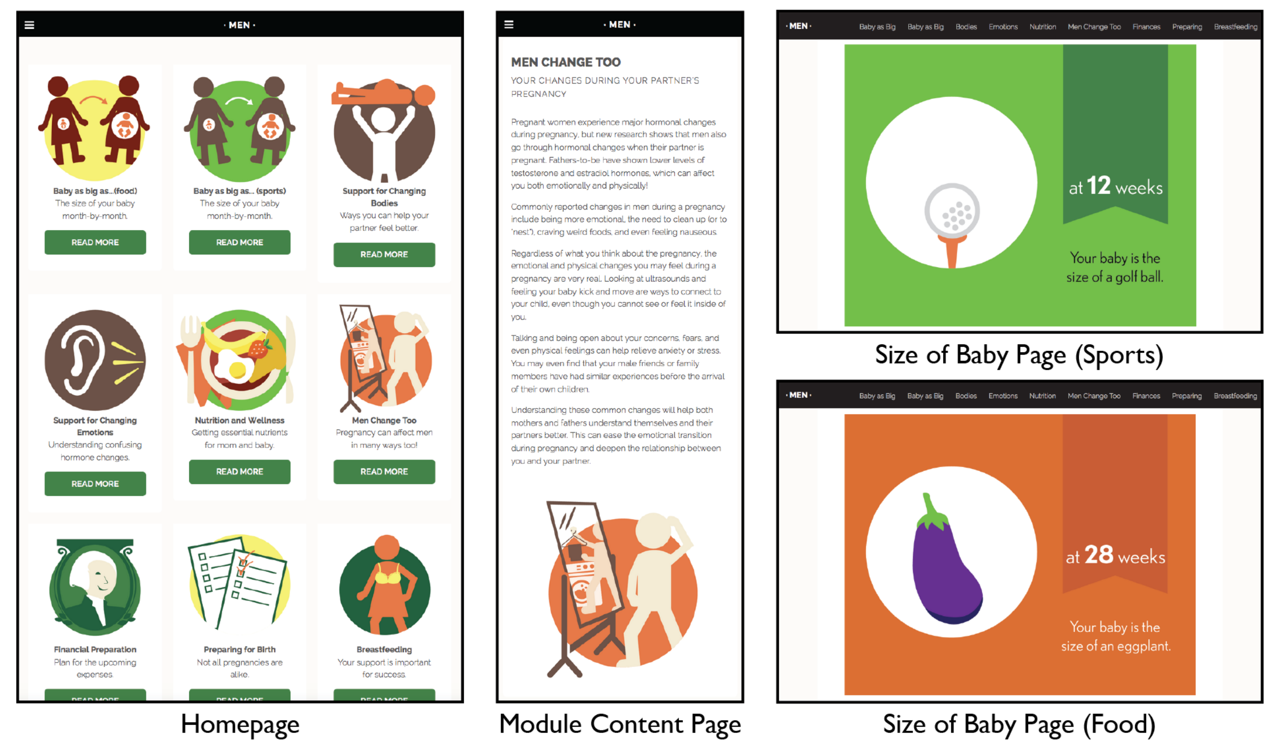
The sample had a mean age of 30.2 (SD 6.3) years and included both fathers (413/962, 42.9%) and non-fathers (549/962, 57.1%). Nearly 12% (115/962) of participants had a partner who was pregnant at the time of the survey. The decision to include all men, not just those who were fathers or seeking to become fathers, was made due to the fact that half of all pregnancies in the United States are unplanned. This is intended as a population-level intervention, where all men in general can benefit from this knowledge.

Overall, 66.0% of the sample identified as white (634/962), 14.0% as African American (135/962), 9.9% as Asian (96/962), and the remainder as biracial, multiracial, or other (97/962, 10.1%). One-quarter (240/962, 24.9%) of the sample had received a high school diploma or GED, 20.9% (202/962) reported having some college experience, and more than half (510/962, 53.0%) reported having a college degree or higher. Most (814/962, 84.6%) agreed that they use the internet to look up health-related information.

Site Development and Measures

The research was modeled after previous studies on the use of technology to engage hard-to-reach populations [16]. Participants were first asked to answer questions surrounding their perceptions of the role of men in pregnancy health, their attitudes toward prenatal health programs, their ideas on how to get men involved in pregnancy, and their use/nonuse of technology when searching for health information.

Figure 1. Screenshot of the Men's Pregnancy Playbook website.



MEN CHANGE TOO

YOUR CHANGES DURING YOUR PARTNER'S PREGNANCY

Pregnant women experience major hormonal changes during pregnancy, but new research shows that men also go through hormonal changes when their partner is pregnant. Fathers-to-be have shown lower levels of testosterone and estradiol hormones, which can affect you both emotionally and physically!

Commonly reported changes in men during a pregnancy include being more emotional, the need to clean up (or to "nest"), craving weird foods, and even feeling nauseous.

Regardless of what you think about the pregnancy, the emotional and physical changes you may feel during a pregnancy are very real. Looking at ultrasounds and feeling your baby kick and move are ways to connect to your child, even though you cannot see or feel it inside of you.

Talking and being open about your concerns, fears, and even physical feelings can help relieve anxiety or stress. You may even find that your male friends or family members have had similar experiences before the arrival of their own children.

Understanding these common changes will help both mothers and fathers understand themselves and their partners better. This can ease the emotional transition during pregnancy and deepen the relationship between you and your partner.

Homepage

Module Content Page

Size of Baby Page (Sports)

Size of Baby Page (Food)

Participants were then directed to navigate through the content. The site was external to the survey, allowing participants to browse and explore the content. The content of the website was written by researchers whose expertise cover perinatal health, health promotion and education, visual communication, and eHealth. The content also reflected information found in the women-focused pregnancy app, My Pregnancy Today, which included an easy-to-understand visual growth chart for fetal development.

The content of the website was intended to span across the prenatal, perinatal, and infancy phases of having a baby—from the time the parents find out about the pregnancy to approximately 1 year of age. The educational modules incorporated themes such as financial preparation, nutritional wellness, breastfeeding information, the importance of a birth plan, and how to recognize obstetric emergencies.

The website was built with a responsive design approach, which ensures content is optimally shown in the users' environment and not platform specific. Drawing from popular social media formatting, participants could access a module's content by clicking on icons, title, or description on the home page or from the navigation bar (see Figure 1). Guidelines from the Centers for Disease Control for ensuring clear communication—such as sufficient use of white space, consistent headings, relevant visuals, and plain language—were followed during development [17].

After exploring the website, participants were asked questions using 7-point Likert scales from 1 (strongly disagree) to 7 (strongly agree). They were also asked open-ended questions related to site content, such as what they found most useful and what could be done to make the content better. The questions were guided by previous work done on engaging men in prenatal and pregnancy health [10,15]. An adequate level of health literacy was found among the sample and was identified using three valid and reliable self-report items reported by Chew et al [18]. All content and survey questions were in English.

Analysis

Both qualitative and quantitative methods were used to analyze the data. Descriptive statistics were used for the quantitative elements of the survey, including means, medians, and standard deviations. A mean score of greater than 5 on a 7-point scale was considered a positive validation. For the qualitative elements, a graduate student researcher and a faculty member of the research team conducted a thematic analysis by independently reviewing each written-in, open-ended answer for relevant and recurring topics.

Results

Results are organized by the relevant themes that emerged during analysis. Results of the 7-point Likert scale items, taken both preexposure and postexposure to the app, are included in Table 1.

Table 1. Pre- and post-website exposure survey questions (N=962).

Item	Preexposure, mean (SD)	Postexposure, mean (SD)
It is important for a father to be involved in pregnancy health.	5.8 (1.4)	
I would attend a prenatal health class at a clinic or doctor’s office.	5.6 (1.4)	
I want to be involved in pregnancy health when the time comes.	5.7 (1.4)	
I believe knowing about pregnancy is useful.		5.8 (1.4)
It is important to know about things that could hurt your baby during pregnancy.		5.8 (1.3)
If I know about things that could hurt my unborn baby, I will try to help my partner avoid them.		5.9 (1.3)
I can take a lot of action to ensure my baby is healthy.		5.8 (1.3)
I am concerned that my baby will not be healthy.		4.9 (1.7)
Complications and unhealthiness can be life-threatening to a baby.		5.8 (1.4)
Complications and unhealthiness can be life-threatening to a woman.		5.8 (1.3)
It is hard to make sure my baby is healthy because I am not the one who is pregnant.		4.9 (1.6)
I thought this website was easy to use.		5.7 (1.3)
This website contained useful information.		5.7 (1.3)
I would use website like this to learn more about pregnancy.		5.6 (1.3)
I would prefer to have this website in an app form.		5.0 (1.6)

Role of Men in Prenatal Health

Participants felt strongly that it is important for a father to be involved in pregnancy health (mean 5.8, SD 1.4) and that it is important to know about things that could hurt an unborn baby during pregnancy, such as second-hand smoke (mean 5.8, SD 1.3). Participants strongly agreed that if they knew about things what could hurt an unborn baby, they would do their best to help their partner avoid them during pregnancy (mean 5.9, SD 1.3). Although most agreed that it could be hard for men to be involved in pregnancy health (eg, getting mixed-messages about what partners want; 583/962, 61.0%), there was strong support for getting positively involved in pregnancy health when the time came in their own lives (mean 5.7, SD 1.4). One participant explained:

> *I have one child and finding information online was a big help. Whenever there were things we didn’t understand immediately we looked online then spoke to doctor to validate at next visit. But I think society in general doesn’t give fathers enough credit and makes them less important so it is easy to be discouraged to be involved...*

Visual Elements and Site Relevance

Participants were asked a series of questions regarding the overall look and feel of the site as well as how relevant the site information was to their lives. The majority of men (698/962, 72.6%) responded positively to the graphics on the site, indicating they liked the overall look of the illustrations and color scheme. Participants agreed that the layout was well structured (mean 5.57, SD 1.35) and that the site looked cohesive (mean 5.47, SD 1.34). The majority also felt that there was “just the right amount of information on the site” (684/962, 71.1%) and that they understood all the information presented (770/962, 80.0%). A participant wrote in:

> *I appreciated the inviting graphic design and clean, simple layout. The site was logically formatted and contained useful and easily digestible information.*

Usefulness of Content and Future Use

Participants were asked how useful and interesting they found each content module (eg, breastfeeding information) and indicated the content on financial preparation was most *useful* (756/962, 79.0%; mean 5.7, SD 1.3) followed very closely by the nutrition information (754/962, 78.4%; mean 5.6, SD 1.3). In terms of what the sample found most *interesting*, the financial preparation module was also highly rated (750/962, 78.0%; mean 5.6, SD 1.3), followed by the module on how to support a partner with changing emotions during pregnancy (732/962, 76.1%; mean 5.6, SD 1.3) and the nutrition information (740/962, 76.9%; mean 5.6, SD 1.3).

Participants generally agreed that they would use this website in the future if they were expecting a baby (698/945, 73.9%; mean 5.3, SD 1.4). The majority (717/950, 75.5%) felt that using a site such as this would improve their ability to plan and prepare for the arrival of a new baby. A respondent wrote in:

> *I like that this website exists at all. I have no idea how to prepare for a baby and this is the kind of website I would look for to prepare for it.*

Most substantially, results indicate that more than three-quarters of the sample said they would share the site with others who would benefit from the information (738/962, 76.7%).

Table 2. Significant differences; fathers versus non-fathers (N=962).

Item	Fathers, mean (SD)	Non-fathers, mean (SD)	*t* test (*df*[a])	*P* value
I think about the health of my family and friends a lot.	5.67 (1.39)	5.28 (1.46)	4.23 (946)	<.001
It is important for a father to be involved in pregnancy health.	6.02 (1.30)	5.70 (1.46)	3.51 (944)	<.001
I would attend a prenatal health class at a clinic or doctor's office.	5.75 (1.37)	5.43 (1.50)	3.29 (946)	.001
I want to get involved in pregnancy health when the time comes.	5.92 (1.13)	5.48 (1.48)	4.84 (941)	<.001
I understand how my partner wants me to be involved in her pregnancy.	5.60 (1.34)	4.90 (1.55)	7.31 (943)	<.001
I use the internet to look up health information.	5.69 (1.37)	5.49 (1.43)	2.11 (941)	.04
This website is designed for someone like me.	5.19 (1.40)	4.86 (1.5)	3.39 (943)	.001
I can relate to the information on this site.	5.44 (1.39)	4.77 (1.51)	7.01 (942)	<.001

[a] *df*: degrees of freedom.

Site Improvement

Participants were asked to write in ways to improve the current website and their suggestions were wide-ranging: from adding videos ("Maybe add a few how-to videos about the pregnancy process and live chat with an expert...") to personalizing the experience by allowing users to input personal information, such as finances, to make the content more tailored. The need for dynamic and interactive information was well represented in their responses. One participant suggested:

> *Provide tools for the financial support: how much does a newborn cost-plug in your numbers and see how it will impact your weekly budget...Really, this is a good resource for men to get involved and take ownership of the pregnancy process, but it seems to be a bit limited on content.*

Another said:

> *This touched the surface, but if I were interested in the financial aspects, give me links to resources to help set up savings plans, budget plans, etc.*

A participant also expressed the want for an easy-to-use checklist:

> *I would like to see a checklist for the arrival of the baby what to buy or what to do the day when it's time to go to hospital to have the baby.*

Several participants suggested adding external links to reputable health care sites or for further reading into the topic. One stated:

> *There should be obvious links in each section when the user wants to learn more about a particular topic there should be (a) more detailed sources and (b) ways to access local resources near the user's location.*

The additions of a search bar to easily search for topics of interest and a forum for health care providers to answer questions were also recommended.

Fathers Versus Non-Fathers

Independent-sample *t* tests were used to find significant differences among respondents. In particular, key differences among those who reported having children versus those who reported not having children were found. Men who indicated that their partners were currently pregnant with their first child were included in the "non-fathers" group for this analysis. Table 2 details the differences between these two groups of participants.

Discussion

Importance of Male Engagement

Increasing positive male involvement in pregnancy is a promising approach to improving maternal and child health outcomes in the United States. International research indicates the inclusion of fathers in prenatal education can help families recognize emergencies and better prepare for birth [5,13]. The level of male involvement during pregnancy is also directly associated with their postnatal engagement [14], which has been found to play a positive role in infant breastfeeding and sleeping best practices. The findings of this particular study answer a call for how to positively engage men in pregnancy health—moving beyond traditional interventions that only target women [19,20]. A preliminary investigation demonstrated the potential of using eHealth to engage men in this issue, and a subsequent study built on that with targeted content developed specifically for men [15,21]. The findings of this national survey confirm this is an effective way to expose men to this important content.

Recurring results show that men—even those who are not yet fathers or thinking about fatherhood—are interested in learning about pregnancy health and ways to ensure their future children are born healthy. The app is intended to be a population-level intervention to improve knowledge of healthy pregnancy behaviors across the general population. In prior studies, all adult males, regardless of sexual orientation, marital status, father status, etc, have been invited to participate. The content of this app is intended for males as partners, but there exist many forms of male involvement in pregnancy, such as being a support system for one's family member in a multigenerational household.

Findings also indicate that men feel unsure of how to be involved and often face barriers such as time and financial constraints. Research on how best to remove these obstacles (eg, by training health care providers on how to make male partners feel welcome) is necessary to move the needle in terms of positive male engagement in pregnancy. Exploring innovative ways to communicate with this difficult-to-reach audience, such as through eHealth, are crucial.

Future Research and Implications

The evaluation of the site was favorable and, perhaps more substantially, three-quarters of participants said they would share the site with others. This suggests a well-designed intervention could spread quickly to disseminate this kind of information. It also suggests an interest and need for content designed to help men meet recognized needs, such as emotional and financial support, during their partner's pregnancy.

Participants' suggestions for improvement represent the logical next steps in development: moving from a relatively small selection of static modules to interactive tools that "live" on a mobile phone as an app. Future iterations can also tailor information based on cultural, socioeconomic, and geographic factors. Social networking and sharing (eg, forums) may also be central to keeping men engaged. Men expressed their willingness to use a similar site in the future, but this study did not track participants' actual behavior over time. Future research must link intent to behavior change in order to give a full picture of the usefulness of this type of intervention.

It is important to point out that, similar to women, men are not a monolith. Tailoring the app's content to various audiences is critical if the content is to resonate. Expanding the app to meet the needs of Spanish-speaking men is a practical next step in development given the population growth of Latinos in the United States. This will require formative research into the cultural nuances of pregnancy that may differ from what is in the current app. By using participant feedback, the content can reach a balance between being broadly applicable and using evidence-based recommendations, but still personalized.

Finally, an app such as this can provide important data for public health researchers and practitioners. Secure data surrounding indicators such as father's attendance at prenatal visits can be collected and analyzed to evaluate the effectiveness of the intervention. This data could inform health care providers' ability to engage fathers during visits, explain the importance of paternal involvement in supporting prenatal health, and help everyone involved consider expectant fathers as important and active partners in supporting maternal and child health.

Limitations

There are several limitations to this study that must be discussed. The first is that this was an online survey and participants were selected through a third-party research firm; as with most research activities, there is potential for biases in response. This survey was available only to men who had internet access and may not have captured the attitudes and beliefs of men who are not online. However, research indicates that nearly 90% of adult males in the United States are online [22]. The minority of men who are not online tend to skew older (>65 years) and are not the target demographic for this eHealth intervention.

Secondly, more than half of the sample (510/962, 53.0%) reported having at least a college degree or higher. This is significantly more than the 32% of US males who hold a college degree [23] and, therefore, the sample is not representative of all education levels. Finally, the survey was presented in English only and may not reflect the attitudes of non-English-speaking US males. The next stage of app development is to release a Spanish version. This will entail going beyond just simple English-to-Spanish translation and will require formative research with Spanish-speaking males to assess their needs as new/expectant fathers.

Although the sample was nationally representative of race/ethnic diversity, the population skewed white: with 66.0% of the sample identifying as white (634/962), 14.0% as African American (135/962), 9.9% as Asian (96/962), and the remainder as biracial, multiracial, or other (97/962). This app is designed for population-level reach, but there may be elements that may not resonate within certain racial/ethnic cultures of the United States.

Lastly, men's perceptions of their roles and responsibilities in pregnancy health may be influenced by factors not assessed in this study. These include cultural norms and perceptions of gender roles, the relationship status of the father and mother during pregnancy, whether the pregnancy was intended or not, and more. Future research should seek to explore these influential factors and how they shape perceptions of positive involvement in pregnancy.

Conclusions

This type of eHealth intervention, particularly once developed and delivered as a mobile app that can include ongoing interaction and data collection, could be a powerful tool for improving maternal and child health outcomes. It also serves as an example of how eHealth interventions can be effectively designed and deployed to reach nontraditional audiences, such as young men, and to address public health issues. Finally, reaching men at the prenatal phase can be considered an early "teachable moment"—where new/expectant fathers are open to information about how to help their partners have a healthy pregnancy and promote the health of their unborn children.

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Conflicts of Interest

None declared.

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Original Paper

How Women Evaluate Birth Challenges: Analysis of Web-Based Birth Stories

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Abstract

Background: Birth stories provide an intimate glimpse into women's birth experiences in their own words. Understanding the emotions elicited in women by certain types of behaviors during labor and delivery could help those in the health care community provide better emotional care for women in labor.

Objective: The aim of this study was to understand which supportive reactions and behaviors contributed to negative or positive emotions among women with regard to their labor and delivery experience.

Methods: We sampled 10 women's stories from a popular blog that described births that strayed from the plan. Overall, 90 challenging events that occurred during labor and delivery were identified. Each challenge had an emotionally positive, negative, or neutral evaluation by the woman. We classified supportive and unsupportive behaviors in response to these challenges and examined their association with the woman's emotional appraisal of the challenges.

Results: Overall, 4 types of behaviors were identified: informational inclusion, decisional inclusion (mostly by health care providers), practical support, and emotional support (mostly by partners). Supportive reactions were not associated with emotional appraisal; however, unsupportive reactions were associated with women appraising the challenge negatively (Fisher exact test, $P=.02$).

Conclusions: Although supportive behaviors did not elicit any particular emotion, unsupportive behaviors did cause women to view challenges negatively. It is worthwhile conducting a larger scale investigation to observe what happens when patients express their needs, particularly when challenges present themselves during labor, and health care professionals strive to cater to them.

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KEYWORDS

patient-centered care; decision making; parturition; women's health

Introduction

Background

The experience of birth is an event that women anticipate and prepare for months in advance. It holds a place of real significance in their lives and that of their baby. Women often approach the birth experience with expectations and trepidation. This is frequently expressed in their birth plans. The most common element of birth plans is pain management [1], but women also express requests regarding atmosphere and postpartum events [2]. Women's plans and wishes for their birth are often communicated to the health care providers to increase coordination around labor and delivery preferences [3]. Birth plans have been shown to empower women, lessen anxiety [4], and lead to greater satisfaction with the birth experience [5], particularly when fulfilled [6]. Furthermore, birth satisfaction is predicted by patient expectations being met [7].

The birth experience, like many other medical experiences, does not always unfold according to expectations. Labor, for example, may involve adverse reactions to medications, risk to the mother's health, or evidence that the baby might be in distress. Any of these events may precipitate the need for an induction, cesarean delivery, or instrumental delivery. These unexpected medical challenges and deviations from the plan can have emotional consequences. Generally, 20% to 33% of women report birth as traumatic [8]. If a birth does not go according to plan, some women experience negative emotions [2]. When coupled with poor support and negative perceptions of care, these women are more likely to experience a traumatic birth [9,10]. A negative emotional experience can have far-reaching consequences, such as hindered cognitive development in children of women who suffered from postnatal depression [11].

The way patients appraise their experiences can influence their health. For example, motivating a person to appraise a stressful situation as a *challenge*, as opposed to a *threat*, leads to better cardiac outcomes and enhanced performance on a stressful task [12]. Appraising a situation less negatively is found to be an effective way of down-regulating negative emotion [13]. Resilient individuals, those able to bounce back from stress, are more likely to use positive appraisals [14], indicating that it is not just the medical challenge per se that determines how the person emotionally evaluates the situation.

Researchers have suggested that satisfaction in the face of challenging medical situations can be increased by patient-centered care. For example, Ford and Ayers [15] analyzed birth stories and found that level of support during birth affects women's mood, anxiety, and perceived control more than stressful interventions (eg, instrumental delivery). Another study showed that pain and medical interventions do not affect birth satisfaction as much as the relationship between the caregivers and the patient [16].

Goals of the Study

In this study, we decided to focus on the interactions that occur in the face of challenges during labor and delivery, as these are more amenable to change through medical training and guidelines than individual patient variables such as patient resilience. We aim to classify these interactions and analyze the association between them and the emotional appraisal of the presented challenges. To do this, we used birth stories women posted on the Web and examined how the interactions present in those stories subsequently influenced the emotions the women experienced.

Sharing information about pregnancy and birth on social media is common practice. A study found that 44.4% of the women surveyed voluntarily posted pregnancy-related information on Facebook roughly once a month, with the goals of documenting the pregnancy (21.3%) and getting advice (28.9%) [17]. Women often also share their birth experiences in a narrative to support other pregnant women, to record their memory of this important life event, or to process the trauma [18,19].

In this study, narratives that women posted on the Web to share with others were specifically selected when the woman's experience did not go according to her formal or informal birth plan. We treated each challenge presented in the women's narratives as a unit of analysis and examined the surrounding supports (or explicit lack thereof) and the ensuing emotional appraisals of these challenges. We used both existing literature as well as the instances of support in the narratives to create a classification system of patient-centered supportive behaviors during labor and delivery. By analyzing women's birth experiences in their own words, our study aimed to create a classification system for support during birth as well as reveal how interactions with women in labor at moments of challenge may influence appraisal of those challenges.

Hypotheses

We hypothesized that we would find examples of emotional support as well as evidence of its importance. Research has shown that physicians who offer emotional reassurance are more effective and appreciated than those who do not [20,21]. Practitioner's empathy can even reduce the duration and severity of the common cold as well as quantitatively increase the immune system response [22]. A qualitative study of patient experience in 14 specialties at Mayo Clinic reveals "empathetic," "humane," "personal," and "respectful" to be among the 7 most important attributes of an ideal physician [23]. A lack of emotional support is also influential: poor emotional support is related to dissatisfaction with the birth experience. In-depth interviews of 10 women who had unexpected birth stories revealed that many of these women felt emotionally uncared for [24]. Furthermore, patient perception of nurses being uncaring is associated with the mother experiencing a birth as traumatic [25].

We also hypothesized that health care providers would provide patients with informational support. Birth experiences are appraised more positively if events are explained, misconceptions are corrected, and questions are answered [26]. Effective physician-patient communication, including information exchange, is related to improved memory, adherence, physiological outcomes, and patient satisfaction [27].

Finally, we hypothesized that health care providers would include women in decision making and management of their medical experience as an additional measure of support. A core value of patient-centered care is the principle of shared decision making: important medical decisions are made by health care providers together with patients, with patients' values and preferences, scientific research, and the physician's clinical expertise being taken into consideration [28]. Not only is patient inclusion considered more ethical, but patient perception of decisional inclusion is also significantly and positively related to patient satisfaction, trust, and understanding [29]. In the case of childbirth, a feeling of control over the birth experience has been directly related to satisfaction [30]. When patients are included in decision making, their sense of personal control and satisfaction with the birth experience increases [16]. Just as decisional inclusion has emotional benefits, exclusion from decision making is associated with emotional difficulties in the patient. A qualitative study by Goldbort [24] found that women's difficulties in feeling in control during unexpected birth experiences often stemmed from a lack of decision-making power. Data from a recent survey of 3000 women showed that women who were consulted before having changes made to their birth plan, and consented to those changes, were more satisfied than those who did not give their consent [31].

Our study explored whether these supports were given not only by health care providers, but also by partners who accompanied the women to birth.

Finally, a research question was whether women would mention additional kinds of support as being given or explicitly missing. In addition, we questioned whether these supports would be associated with the emotional appraisal of the challenges.

Methods

Sample

The sample for this study consisted of 10 birth stories, each publicly posted by different women on the internet blog, This West Coast Mommy [32]. This blog is the number 7 Google search result for "Sharing Birth Stories" out of over 8,000,000 hits on Google. This particular blog has about 60 stories archived and receives about 40,000 visitors a month (O Lasting, unpublished data, January 2018). This website encourages women to submit their birth story to share with other women in Canada and the United States. The instructions on the blog read:

> *I'm interested in all your stories: natural or medicated birth, vaginal or C-section or VBAC, home or hospital, premature or full-term, orgasmic birth or birth trauma, adoption or surrogate or miscarriage. Did everything go as planned or were your expectations smashed to pieces? What would you change or do the same next time around? I reserve the right to edit for length (please aim for somewhere between 400-1000 words) or clarity, but you have the final say in how your story is published.*

The editor clarified that she does not screen out any stories and "lightly edits at times for length or clarity" (O Lasting, unpublished data, October 2017).

We chose the 10 most recent stories that mentioned a diversion from the birth plan between the onset of labor and the baby's first feeding. Stories had a range of 638 to 1799 words (mean 1224.60, SD 454.20).

Coding

After independently reading a handful of stories, an initial coding scheme was agreed upon to capture events, supports, and appraisals. After independently coding each story, 2 of the authors met to agree on any discrepancies to reach 100% agreement and further refine the coding scheme if needed. A third author provided feedback on the coding scheme and acted as an additional reviewer when coding discrepancies or questions arose. To ensure the specificity of the coding scheme, percent agreement was calculated on one of the stories (approximately 10% of the events) and was reported to be 86%.

Coding applied to the birth experience, which extended from the onset of labor or induction to the baby's first feeding. Thus, neither interactions with the health care provider before labor nor postpartum events in the hospital after the baby's first latch or bottle were included.

Our focus was challenges experienced during birth. As such, we did not consider events that were described by the woman as neutral or positive; events were identified as challenges when these reflected negative or unclear emotional valence. An example of a challenge was:

> *I woke up after a few solid few hours of sleep and the pain was back, just as intense as before the epidural. I was 6 cm dilated, and the contractions were horrible...*

On the other hand, this is an example of an event that was not coded as a challenge:

> *I was 4 cm dilated when I was first examined at the hospital.*

We recorded if medical action was taken in response to the challenge (eg, analgesia administered or blood pressure measured). We then coded supportive or unsupportive reactions in response to each challenge. We further coded for the woman's appraisal of her physical state (physical resolution) after any supportive (or unsupportive) reactions. If the woman attached a conclusion regarding her physical condition to the challenge, such as "I felt better," this would be coded as positive physical appraisal. Alternatively, "my back hurt even more" would be coded as a negative physical appraisal. If there was no physical appraisal, the event was coded as missing or "neutral" physical appraisal.

Thereafter, we coded for emotional appraisals after any supportive or unsupportive reactions. An expression of emotion (eg, fear or anger) or a summary evaluation of the challenge that carried a clear affective valence was considered an emotional appraisal. For example, if the woman expressed that she "felt empowered," this would be coded as positive emotional appraisal. Alternatively, "I was terrified" would be coded as a negative emotional appraisal. If there was no emotional appraisal, the event would be coded as missing emotional appraisal or "neutral." Events could also be coded for mixed emotional appraisal:

> *The minute she finished that sentence I instantly burst into tears. I was happy. I was petrified. I was anxious. I think I felt every single emotion all at once, right at that moment.*

A given event could have both physical and emotional appraisals. Consider, for example:

> *It hurt so bad, so I got an epidural. It helped the pain, but I felt so guilty about my decision.*

Here, a woman describes a positive physical appraisal but a negative emotional appraisal (she felt guilty).

Ethics Approval

This research project received ethical approval from the Ono Academic College. Note that we analyzed women's birth stories that were freely available on the Web. No identifying information on the women was provided to us and none is included in the analysis.

Results

The Challenges

The stories were a sample of diverse birth experiences (see Table 1 for the types of experiences found in each story). Although the majority of the stories mentioned a spontaneous start of labor at home (contractions and/or water broke), 4 out of the 10 births ended in unplanned cesarean sections, and 6 of the 10 involved artificial induction of labor. Of the 7 women who planned to avoid an epidural, 6 ultimately received an epidural.

Overall, 90 events (challenges) were identified in the 10 stories. Each story had between 2 and 18 events (mean=9). The challenge of discomfort (pain, nausea, and exhaustion) occurred in every story and made up 38% (34/90) of all events. Medical issues related to the mother (eg, epidural side effects, artificial induction, failure to progress, and deviations in blood pressure) contributed to 29% (26/90) of all events and appeared in every story. Medical issues related to the baby (eg, fetal positioning or fetal distress) presented in 6 stories and contributed to 13% of all events. Managing fear and concern (6/90, 7%), problems with monitors (4/90, 4%), having to wait (4/90, 4%), and challenging interactions with health care providers (4/90, 4%) were each found in 3 of the stories (see Table 2).

The Reactions

Some challenges were handled by responding medically (eg, distributing medication or using a vacuum). In 27% (24/90) of the events, there was medical action taken in response to the challenge. See Table 3 for which reactions were given by whom.

Following 53% (48/90) of the challenges, a supportive or unsupportive reaction took place. On the basis of our hypotheses, we identified 3 different types of reactions that could either be supportive or unsupportive: informational (woman is given information or if unsupportive, woman lacks information or comprehension), decisional inclusion (woman is included in decision making or if unsupportive, woman explicitly reports being left out of the decision, not having control, or being dismissed), and emotional (validation, affirmation, or empathy expressed or if unsupportive, a disregard or dismissal of feelings). The birth stories also revealed an additional type of support: practical support. We coded practical support as assisting the mother in nonmedical ways. Examples of practical support could be giving water to the mother or getting the mother a pillow. Similar to the other categories, the mother could also have an unmet need for practical support.

Table 4 provides examples of the different reactions to challenges. Informational support was health care providers' most common reaction to challenges. In the following example, the doctor provides informational support, explaining why an induction is needed. The woman is scared, but her partner steps in with emotional support, and she is able to accept the situation:

> *He told me that I needed to be induced as soon as possible because my high blood pressure was very dangerous for both me and my baby...I was so scared. I looked at Bryan, and he grabbed my hand when he saw the look on my face. He told me, "You are going to do so good." That's all I needed to hear. I agreed to the induction.* [Story #1]

The above example illustrates how different constituents tend to support the mother in different ways. In our analysis, emotional support was solely provided by partners, and 83% (10/15) of the instances of practical support were also provided by partners. In contrast, 95% (19/20) of instances of informational support and 73% (11/15) of instances of decisional inclusion were given by health care providers.

Table 1. Details of the ten birth stories.

Story	1	2	3	4	5	6	7	8	9	10
Words (mean 1224, SD 454.20), n	1799	1432	1622	688	640	638	1550	961	1642	1274
Events (mean 9, SD 3.94), n	18	9	9	10	9	7	7	2	10	9
Intentions for birth										
Planned for natural birth (n=4[a])	No	No	No	Yes	No	Yes	Yes	No	Yes	Yes
Planned to avoid epidural (n=6)	Yes	No	No	Yes	No	Yes	Yes	No	Yes	Yes
Actual birth										
Received epidural (n=8)	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Spontaneous start of labor (or water broke) at home (n=7)	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
Induction (n=6)	Yes	Yes	No	Yes	Yes	No	No	No	Yes	Yes
Emergency cesarean section (n=4)	No	No	No	No	Yes	No	No	Yes	Yes	Yes
Hemolysis, elevated liver enzyme, low platelet syndrome (n=3)	No	No	No	No	Yes	No	No	Yes	Yes	No
Paralysis (n=1)	No	No	Yes	No	No	No	No	No	No	No
Premature baby (n=2)	No	No	No	No	No	No	No	Yes	Yes	No

[a] n values refer to the number of stories that reported these events.

Table 2. Emotional and physical appraisals for various types of challenges.

Challenges	Patient appraisal				Examples of challenges
	No appraisal (neutral)	Negative	Positive	Mixed	
Discomfort (N=34), n (%)					
Emotional resolution	29 (85)	3 (9)	2 (6)	0 (0)	“The magnesium drip was awful. I felt rotten. I was instantly weak, queasy, and hot. Hot as hell.”
Physical resolution	26 (77)	3 (9)	5 (15)	0 (0)	
Medical issues of mother (N=26), n (%)					
Emotional resolution	16 (82)	5 (19)	4 (15)	1 (4)	“The epidural failed and a spinal had to be done.”
Physical resolution	19 (73)	3 (12)	4 (15)	0 (0)	
Medical issues with the baby (N=12), n (%)					
Emotional resolution	7 (58)	2 (17)	2 (17)	1 (8)	“The nurse told us the baby was facing the wrong direction.”
Physical resolution	8 (67)	2 (17)	1 (8)	1 (8)	
Fear or overwhelmed (N=6), n (%)					
Emotional resolution	1 (17)	1 (17)	2 (33)	1 (17)	“I was unable to see my son...I was terrified wondering if he was doing okay and I was so afraid...”
Physical resolution	4 (67)	0 (0)	1 (17)	0 (0)	
Difficult interactions (N=4), n (%)					
Emotional resolution	3 (75)	1 (25)	0 (0)	0 (0)	“A nurse began to check my belly for sensation with an ice cube. ‘Can you feel this?’ ‘Yes.’ ‘No you can’t.’ ‘Wait, what?’ Why bother asking me if you aren’t going to believe my answers?”
Physical resolution	2 (50)	1 (25)	1 (25)	0 (0)	
Problems with monitor (N=4), n (%)					
Emotional resolution	3 (75)	0 (0)	1 (25)	0 (0)	“They were having trouble finding the baby’s heart rate...”
Physical resolution	3 (75)	0 (0)	1 (25)	0 (0)	
Waiting (N=4), n (%)					
Emotional resolution	2 (50)	2 (50)	0 (0)	0 (0)	“After waiting two hours in a small triage room, with not a single nurse checking in on me...”
Physical resolution	2 (50)	1 (25)	1 (25)	0 (0)	

Table 3. Supportive and unsupportive interactions with different constituents.

Reactions	Doctor	Nurse	Midwife	Health care provider (unspecified)	Doula	Partner	Overall
Supportive reaction, n (%)							
Decisional	2 (13)	1 (7)	1 (7)	7 (47)	2 (13)	2 (13)	15 (100)
Informational	9 (45)	3 (15)	2 (10)	5 (25)	1 (5)	0 (0)	20 (100)
Emotional	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	3 (100)	3 (100)
Practical	0 (0)	0 (0)	0 (0)	1 (8)	1 (8)	10 (83)	12 (100)
Unsupportive reaction, n (%)							
Decisional	2 (50)	1 (25)	0 (0)	1 (25)	0 (0)	0 (0)	4 (100)
Informational	1 (17)	0 (0)	0 (0)	5 (83)	0 (0)	0 (0)	5 (100)
Emotional	0 (0)	0 (0)	0 (0)	1 (100)	0 (0)	0 (0)	1 (100)
Practical	0 (0)	1 (100)	0 (0)	0 (0)	0 (0)	0 (0)	1 (100)

Table 4. Examples of supportive and unsupportive reactions.

Type of supportive or unsupportive reaction	Supportive reactions[a]	Unsupportive reactions[a]
Informational	“He [the doctor] told me *that I needed to be induced as soon as possible because my high blood pressure was very dangerous for both me and my baby. He told me I needed a magnesium drip.*” [Story #1]	“While I was in Triage, the nurse discovered my blood pressure was extremely high. I was kept in Triage and not sent to a Labor and Delivery room. *To this day I do not really understand why,* but my best guess is they were afraid my baby would be in distress and I would have an emergency c-section.” [Story #7]
Decisional input	"The doctors came in to do an exam. *They said I was 4 cm and that they would like to start oxytocin, “but your birth plan...” ”My what? Pff, don’t liksten to that. Do what you think is right, just tell me about it first,” “Okay, we would recommend an epidural with the oxyto—” “Yep, let’s get that going.* [Story #2]	“I was told she couldn’t administer the epidural until I was not in a contraction. She began preparing, and *I said, “I’m contracting,” but she went ahead anyway*.” [Story #3]
Emotional	“I was so scared. I looked at Bryan, *and he grabbed my hand when he saw the look on my face. He told me, ‘You are going to do so good.’* That’s all I needed to hear. I agreed to the induction,” [Story #1]	“After waiting two hours in a small triage room, with *not a single nurse checking in on me* I was feeling such dread.” [Story #10]
Practical	“I woke up at one point and yelled, ‘I’m going to barf!’ *My husband came running over with a take-out french fry tray* just in time for the barf to hit it like a skateboard ramp and go spewing across everything.” [Story #2]	“*...*that situation they put me in was stressful: waiting with no updates, alarms ringing every 15 minutes, *strapped to a bed and needing to use the bathroom, a pillowcase full of towels as they were out of pillows...*” [Story #10]

[a] Quotes are taken directly from the birth story without editing. Italics denotes the reaction, or sometimes, as in the case of unsupportive reactions—lack thereof.

Table 5. Others’ reactions to challenges and patients' ensuing emotional appraisals.

Reactions	No appraisal (Neutral, N=61), n (%)	Positive appraisal (N=11), n (%)	Negative appraisal (N=15), n (%)	Mixed appraisal (N=3), n (%)
Supportive reaction	29 (48)	7 (64)	5 (33)	2 (66)
Decisional	9 (15)	1 (9)	3 (20)	0 (0)
Informational	11 (18)	4 (36)	2 (13)	1 (33)
Emotional	0 (0)	2 (18)	0 (0)	1 (33)
Practical	9 (15)	0 (0)	0 (0)	0 (0)
Unsupportive reaction	6 (10)	0 (0)	5 (3)	0 (0)
Decisional	2 (3)	0 (0)	2 (13)	0 (0)
Informational	3 (5)	0 (0)	3 (20)	0 (0)
Emotional	1 (2)	0 (0)	0 (0)	0 (0)
Practical	0 (0)	0 (0)	0 (0)	0 (0)
Medical action taken	21 (34)	2 (18)	1 (7)	0 (0)

The events were also coded for both emotional and physical appraisals following the challenge and reactions. Most of the events (61/90, 68%) concluded with no emotional appraisal (neutral). Some events (11/90, 12%) concluded with positive appraisal, some events (15/90, 17%) concluded with a negative emotional appraisal, and some (3/90, 3%) events concluded with clearly mixed emotions (mixed resolution).

Most (65/90, 72%) events did not have a physical appraisal, 5 events (6%) concluded with a positive physical appraisal (eg, pain got better and baby was delivered successfully), 10 events (11%) concluded with negative physical appraisal (eg, “stuck in bed” and overwhelming pain), and 1 event (1%) concluded with mixed physical appraisal. Table 5 shows how different appraisals were related to different types of support.

A given event could be coded as having any of the reactions above (or any combination thereof).

Whether or not a patient received positive support did not affect the type of appraisal attached to the event. However, if a patient received an unsupportive reaction, appraisal attached to the event was affected (Fisher exact test, *P*=.02; see Table 6).

Table 6. Proportions of different types of patient emotional appraisals resulting from different reactions.

Reaction	No appraisal (neutral)	Positive appraisal	Negative appraisal
Supportive[a] reaction[b], n (%)			
Reported	29 (71)	7 (17)	5 (12)
Not reported	32 (73)	5 (11)	7 (16)
Unsupportive reaction[c], n (%)			
Reported	6 (55)	0 (0)	5 (46)
Not reported	60 (74)	11 (14)	10 (12)

[a] Support includes informational, decisional, emotional, or practical.

[b] Fisher exact test, P=.66, *nonsignificant.*

[c] Fisher exact test, P=.02.

Discussion

Principal Findings

Our study examined 10 birth stories that included 90 total challenges to the women during the childbirth process. These challenges included facing dangerously high blood pressure, premature delivery, and pain too intense to continue with the medication-free birth plan. Using each challenge and the related reactions and emotional appraisals as the unit of analysis allowed us to closely examine the psychosocial antecedents of how these women in labor emotionally evaluated each challenge. By analyzing women’s birth experiences in their own words, our study offers a classification system for support during birth and highlights how avoiding unsupportive interactions with women in labor at moments of unexpected challenge is crucial in helping women give these challenges a neutral or positive emotional resolution.

Consistent with our hypotheses, as well as on emergent findings from the stories, we determined that there were 4 types of supportive (or unsupportive) interactions that could take place when a woman in labor is faced with a challenge: emotional, decisional, informational, and practical (the last category identified from the data). Each challenge is an opportunity to support the mother.

Providing support did not mean interfering with the medical course of events. It did, however, involve catering to the woman’s needs for information, decisional inclusion, practical assistance, or emotional reassurance. For example, when a woman who had an epidural needle inserted twice was informed that this occurred because she was shaking (information), she accepted the answer and the challenge was resolved with emotional neutrality. In our analysis, practical support was the most common support partners gave, whereas health care providers gave nearly all instances of informational support and most instances of decisional inclusion.

Labor and delivery are composed of a string of challenges that need to be managed dynamically and cannot always be anticipated ahead of time. Notably, the medical challenges women face do not always determine the emotional outcome. For example, challenges that involved medical threats to the baby were equally likely to be resolved with positive or negative appraisal. When challenges involved medical issues of the mother, emotional appraisals were also nearly balanced between positive and negative. Note that in both cases, emotional appraisals for most challenges were missing. This was interpreted as neutral resolution, suggesting that the woman may have accepted the challenge and moved on.

Our data suggest that when women are responded to in an unsupportive way, they are more likely to evaluate the challenge with negative emotion. When unsupportive reactions were reported, the emotional appraisal of the challenge was 3.7 times more likely to be negative than if no unsupportive reactions were reported. The result that unsupportive reactions carried more weight than supportive reactions on women’s emotional evaluations of the challenges is not surprising. Research has shown that humans have a tendency to react more strongly to and be more emotionally affected by negative events than positive events [33,34]. Our data show that the most common unsupportive reaction reported by women was a lack of informational support:

> *But...the baby wasn’t crying. They swept her up and rushed her down the hall to the nursery. I was so scared. I cried as I said over and over, ‘’Where’s my baby? Is she okay?” They kept telling me she just needed some extra help.*

In this example, the woman is not given a proper answer and is distraught because of the lack of information.

Our results are somewhat aligned with research showing that negative interpersonal events, consisting mostly of lack of support (eg, being ignored and feeling unsupported or abandoned), were the strongest predictor of traumatic birth experiences [35]. A third of women report this [9]. Although challenging intrapartum events such as an unplanned cesarean can predict adverse responses to childbirth, this is not a necessary condition. Traumatic feelings can also arise following normal vaginal deliveries [36].

Thus, as our study suggests, **s**atisfaction is determined more by how the challenges that arise are handled than by the nature of the challenges themselves. Indeed, a meta-analysis of women’s experiences highlights that feelings of trauma can result from a lack of a relationship with health care providers, poor communication, and care that leads women to feel dismissed or out of control [37]. Although many women hear the phrase "all that matters is a healthy baby," mounting evidence suggests that a patient-centered approach can improve medical outcomes [38] and increase satisfaction with the childbirth experience, ultimately leading to better mental health and family outcomes [39].

Given the unpredictability of birth, some health care providers are reluctant to *plan* the birth experience [5,40]. However, the research reviewed above suggests that an informed, empowered woman is beneficial to the childbirth process. Our study adds to this knowledge by showing that challenges that present during labor and delivery do not necessarily lead to a negative emotional appraisal. The provision of support serves to mitigate the inherent negative effect challenges can have.

Limitations

Our study has a few limitations. First, the information that the women share in their birth stories is likely what was salient in their memory, and their interpretation of the events is not necessarily an accurate portrayal of the experience [41,42]. Nonetheless, previous work has indicated that a woman's perception of what occurred is relatively accurate, even over time. For example, Simkin [43] found that women's memories of labor, particularly the actions of doctors, nurses, and partners, are "generally accurate, and many are strikingly vivid." Furthermore, research shows that patient perceptions of an event have importance. These perceptions linger, influencing emotions and potentially future decision making. For example, colonoscopy patients' evaluation of the procedure was associated with their willingness to repeat the procedure in the future [44]. However, the data women share must be interpreted cautiously. It would be a mistake to only use women's recollections to surmise what physicians are or are not doing.

Second, we only analyzed the birth experiences of 10 women, albeit in depth, and can hardly presume they are a representative sample of women giving birth. Our aim in this study was to look at challenges as subjectively defined by the women experiencing them. Our study provides careful insight into the ways in which support, even during a potentially unpleasant event such as having an epidural needle inserted twice, can be perceived as having an emotionally neutral resolution. Furthermore, there might be selection bias in that these women have chosen to share their birth stories on the Web. Firestone et al similarly found that a self-selection bias exists among internet-based birth cohort studies [45]. Another possible insertion of bias involves the types of women who post on internet blogs. A study by Chilukuri et al found that low-income pregnant women are less likely to access most internet technologies than women at high-income levels [46]. Although the hemolysis, elevated liver enzyme, low platelet (HELLP) syndrome occurred in 3 out of the 10 women in our sample, this does not reflect the general population, where HELLP syndrome occurs in about 0.7% of pregnancies [47].

Finally, we only coded from the onset of labor to the babies' first feeding. We, therefore, did not code for support that happened after birth such as in a follow-up appointment. Simple validation of feelings about the loss of a plan might help women cope better, and that may have happened the day after delivery. It is known that debriefing after a traumatic birth experience may reduce negative appraisals [48,49]. Limitations notwithstanding, ours is an in-depth examination of the challenges women encounter during birth, as told of their own initiative and in their own words. This provides us a powerful way of glimpsing into the patients' experience.

Conclusions

Future research should examine how individual variables, such as need for control or need for cognition, might interact with support. Women are not all the same in how they respond to others' attempts at supportive behavior. For example, 1 woman was overwhelmed by a tour of the neonatal intensive care unit the day she was going to give birth to a premature baby:

> *The very next day I was wheeled into the NICU [neonatal intensive care unit] unit for a tour. I do not think anything in this world could have prepared me for that. I was taken into Pod 6 where the NICU nurse wanted to show me the approximate size my son would be when he was delivered. The baby was so tiny and delicate and hooked up to so many machines! There were alarms going off everywhere with nurses assisting the babies in need. I held my breath to hold back the tears. When I was wheeled into my room I lost it. I was inconsolable.*

For others, informational support was comforting. Our data showed that informational support was twice as likely to lead to positive appraisal than negative appraisal.

In conclusion, by analyzing women's accounts of their birth experiences in their own words, our study offers a classification system for support during labor and delivery and highlights the need to avoid unsupportive interactions with women in labor when unexpected challenges present themselves. Although challenges are unavoidable, we hope to have made a small contribution toward making them less emotionally painful.

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Conflicts of Interest

None declared.

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Abbreviations

HELLP: hemolysis, elevated liver enzyme, low platelet
NICU: neonatal intensive care unit

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Original Paper

Sudden Infant Death Syndrome and Safe Sleep on Twitter: Analysis of Influences and Themes to Guide Health Promotion Efforts

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Abstract

Background: In the United States, sudden infant death syndrome (SIDS) is the leading cause of death in infants aged 1 month to 1 year. Approximately 3500 infants die from SIDS and sleep-related reasons on a yearly basis. Unintentional sleep-related deaths and bed sharing, a known risk factor for SIDS, are on the rise. Furthermore, ethnic disparities exist among those most affected by SIDS. Despite public health campaigns, infant mortality persists. Given the popularity of social media, understanding social media conversations around SIDS and safe sleep may assist the medical and public health communities with information needed to spread, reinforce, or counteract false information regarding SIDS and safe sleep.

Objective: The objective of our study was to investigate the social media conversation around SIDS and safe sleep to understand the possible influences and guide health promotion efforts and public health research as well as enable health professionals to engage in directed communication regarding this topic.

Methods: We used textual analytics to identify topics and extract meanings contained in unstructured textual data. Twitter messages were captured during September, October, and November in 2017. Tweets and retweets were collected using NUVI software in conjunction with Twitter's search API using the keywords: "sids," "infant death syndrome," "sudden infant death syndrome," and "safe sleep." This returned a total of 41,358 messages, which were analyzed using text mining and social media monitoring software.

Results: Multiple themes were identified, including recommendations for safe sleep to prevent SIDS, safe sleep devices, the potential causes of SIDS, and how breastfeeding reduces SIDS. Compared with September and November, more personal and specific stories of infant loss were demonstrated in October (Pregnancy and Infant Loss Awareness Month). The top influencers were news organizations, universities, and health-related organizations.

Conclusions: We identified valuable topics discussed and shared on Twitter regarding SIDS and safe sleep. The study results highlight the contradicting information a subset of the population is exposed to regarding SIDS and the continued controversy over vaccines. In addition, this analysis emphasizes the lack of public health organizations' presence on Twitter compared with the influence of universities and news media organizations. The results also demonstrate the prevalence of safe sleep products that are embedded in safe sleep messaging. These findings can assist providers in speaking about relevant topics when engaging in conversations about the prevention of SIDS and the promotion of safe sleep. Furthermore, public health agencies and advocates should utilize social media and Twitter to better communicate accurate health information as well as continue to combat the spread of false information.

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KEYWORDS

sudden infant death; sudden unexpected infant death; accidental suffocation in a sleeping environment; infant mortality; safe sleep; sleep environment; social media; Twitter; health communication; public health

Introduction

Sudden infant death syndrome (SIDS) is the leading cause of death in infants aged between 1 month and 1 year and the third leading cause of infant mortality in the United States [1]. Approximately 3500 infants die every year due to SIDS and sleep-related reasons [2]. Causes of sleep-related deaths include SIDS, accidental suffocation and strangulation in bed (ASSB), and ill-defined deaths [2].

While there was a marked decline in sleep-related deaths following the American Academy of Pediatrics (AAP) recommendations for supine sleep position in 1994, this decline has since lost momentum [2-4]. Furthermore, there appears to be an increase in the number of unintentional sleep-related deaths in infants. For example, infant mortality rates due to ASSB have quadrupled since 1984 [5]. While bed sharing is a known risk factor for infant death [6], bed sharing has increased in the United States, with 50%-61% of mothers admitting to bed sharing at some point [6,7] and African American women specifically bed sharing with infants for perceived safety, improved infant sleep, and convenience [4,8].

To make matters more complex, sociocultural differences among sleep behaviors and mortality rates persist. For instance, populations at the highest risk for infant mortality due to SIDS and sleep-related deaths exhibit the following characteristics: lower socioeconomic status, uneducated, younger age of birth mother, smoking during pregnancy, and African American or American Indian or Alaskan ethnicity [1,9,10].

In 2016, the AAP updated their recommendations for the prevention of SIDS and sleep-related infant deaths [2]. However, despite ongoing communication efforts, there appears to be a gap between public health recommendations to prevent SIDS and promote safe sleeping environments and what parents are actually practicing with regard to infant sleeping environments, as evidenced by the continued infant mortality statistics [1]. Media coverage of recommendations, as well as social media conversations around SIDS and safe sleep, has the potential to spread, reinforce, or counteract public health recommendations.

Analyzing social media, an incredibly popular and useful tool with wide-reaching capabilities, allows for a better understanding of some beliefs and exposure to information regarding SIDS and may, therefore, assist in the development of more effective public health programs. As of 2015, approximately 65% of American adults use social media [11]. A recent trend reflects that people are also using social media for health information. According to the Health Information National Trends Survey (HINTS), a survey that tracks health communication and information technology of American adults, social media was found to penetrate all persons despite race, education, or health care access [12]. This finding is also supported by studies demonstrating the widespread use of social media among parental groups [13-18].

Moreover, Twitter is gaining popularity and is used by 24% of American adults [19]. The average Twitter user tends to be younger (36% of those aged between 18 and 29 years use Twitter) [19]. Twitter use spans educational levels, although those with college degrees use it more than those with a high school degree or less (29% vs 20%) [19]. In one study of primarily female (76%), African American mothers (41%), 12.5% participants used Twitter daily [20]. Understanding Twitter's users is essential when considering the health issue of SIDS, given that SIDS impacts African American people disproportionately more than other ethnicities [1,2,9].

Therefore, there is an opportunity to use social media platforms, like Twitter, for listening to subgroups of the public, as well as for health promotion. In addition, Twitter can be used to assess the public's response and shape the public's perception of a health issue, thereby allowing health communicators to more effectively plan and implement response strategies [21,22]. Moreover, Twitter can assist policy makers and governmental agencies in understanding the information that is being spread and in potentially combating the spread of false information [23]. Furthermore, Twitter is an ideal form of social media for analysis given that the posts are public.

The purpose of our study was to better understand social media conversation around SIDS to understand possible influences and guide health promotion efforts. The remainder of this paper outlines the specific study methods, findings, and implications of this work for public health research and practice.

Methods

Text Analytics and Data Acquisition

We used textual analytics to identify topics and extract meanings contained in unstructured textual data. Twitter messages were captured for 3 months—September, October, and November 2017. Tweets and retweets were collected using NUVI software (NUVI, Lehi, UT, USA) in conjunction with Twitter's search API (application programming interface). Because our focus was on SIDS, keyword combinations were selected to avoid biased language used by different audiences, filter irrelevant information, and increase the likelihood of capturing a greater signal-to-noise ratio for the topic under investigation. We used the following keywords or phrases to capture relevant Twitter messages: "sids," "infant death syndrome," "sudden infant death syndrome," and "safe sleep."

The keywords returned a total of 41,358 messages. There were 5282 messages in September 2017, 13,438 in October, and 22,638 in November. Then, we analyzed the messages using text mining and social media monitoring software, SAS Text Miner 12.1 (SAS Institute Inc, Cary, NC, USA) [24] and NUVI

[25], and interpreted the findings. NUVI is a social listening tool that allows for the monitoring of messages from Twitter using basic aggregation tools based mainly on the frequency and reach of users, posts, and keywords. Using NUVI, the tweets were analyzed for trending hashtags, top influencers (determined primarily by the number of followers and frequency of mentions and retweets), and location of tweets by state and per capita (analyzed using a combination of geo-tagging and specific locations associated with the Tweeter's bio). The use of publicly available data in this study did not require approval from our Institutional Review Board.

Text Analytics

The tweets' textual content was analyzed using SAS Text Miner 12.1 [24]. SAS Text Miner is an algorithm-driven statistical software used to uncover and understand information. SAS Text Miner provides the ability to parse and extract information from text, filter and store the information, and assemble tweets into related topics for introspection and insights from the unstructured data [26,27].

The first step was to extract, clean, and create a dictionary of words using a natural language processor. Using a Text Parsing node, each message was divided into individual words; these words were listed in a frequency matrix, and words that contributed little to the understanding of the topic, such as auxiliary verbs, conjunctions, determiners, interjections, participles, prepositions, and pronouns, were excluded from the analysis. Following this, a Text Filter node was used to exclude words that appeared in <4 messages as a conservative measure to reduce noise. A single author with the knowledge of the subject matter visually inspected and manually removed irrelevant terms. The words initially included (and excluded) in the analysis were visually inspected to ensure accuracy and identify unrecognizable symbols and letter groups for exclusion.

With the inclusion criteria set, a Text Topic node was used to combine terms into 8-12 topic groups. This clustering divided the document collection into mutually exclusive groups based on the presence of similar themes using expectation maximization clustering. After visually examining each of the created topics, 10-, 11-, and 8-topic solutions most clearly illustrated the main themes for September, October, and November, respectively. Finally, the researchers reviewed the individual messages of the final topic groups to interpret the final themes. This was accomplished by individually reviewing the actual messages from each cluster or topic to arrive at the description that is now contained in the tables identifying the themes.

Results

Themes

Data on SIDS and safe sleep tweets for the months of September, October, and November 2017 have been presented in Tables 1-3, respectively.

A major theme identified was safe sleep recommendations. In September and October, 3 of the topics included recommendations for safe sleep to prevent SIDS, including the updated AAP recommendations. In November, just 2 of the topics included recommendations for safe sleep to prevent SIDS, including the AAP recommendations. In September, some of these messages originated from public health agencies, including a video from the National Institutes of Health promoting safe sleep, and statewide efforts to reduce SIDS. This was slightly different from October, where a popular story originated from CNN and included advertising for sleep products, such as Dr Harvey Karp's responsive bassinet, Snoo. In November, the safe sleep messaging originated from public health agencies, including statewide efforts to reduce SIDS; however, some of them were also personal recommendations on infant sleep and SIDS prevention.

Table 1. Sudden infant death syndrome (SIDS) and safe sleep tweets by topic for September 2017.

Topic	n (%)	Description
+sleep,+safe,safe sleep,baby,+share	459 (8.69)	Safe sleep recommendations to reduce SIDS (some originating from public health agencies, some about recent studies on SIDS)
sudden,syndrome,sudden infant death syndrome,+death,+infant	428 (8.10)	Explanations for SIDS (vaccines cause Autism, brainstem abnormality causes SIDS, cardiac-mediated SIDS), Web-based community fundraising for SIDS, baby box initiatives, and the American Academy of Pediatrics (AAP) guidelines on safe sleep
Institute,+american,support,charity,+cause	219 (4.15)	Web-based fundraising for the American SIDS Institute
Research,+confirm,+brain,chemistry,babies' brain	212 (4.01)	Australian study links brain chemical to SIDS
undesa,political leadership,parisagreement,cop,political	112 (2.12)	AAP recommendations for safe sleep and unrelated posts regarding small island development
doritmi,emmagpaley,nicolasdenver,badzoot7,markjarthur	104 (1.97)	Explanations for SIDS (vaccines cause SIDS, vaccines do not cause SIDS) and daycare complies with safe sleep guidelines
Grateful https,penny,funeral,grateful,217xxmvzmk	88 (1.67)	Fundraising for SIDS and general information about SIDS
Huffpost,easy,a-alone,b-back,c-crib	87 1.65)	Safe sleep recommendations to reduce SIDS
+back,williamdevry1,nancyleegrahn,julexis,gh	72 (1.36)	Explanations for SIDS (vaccines cause SIDS)
maine,vaccine,mcvc,dhhs,+notify	68 (1.29)	Explanations for SIDS (vaccines cause SIDS)

Table 2. Sudden infant death syndrome (SIDS) and safe sleep tweets by topic for October 2017.

Topic	n (%)	Description
+baby,+sleep,+sleep,+child,+safe	1549 (11.53)	Safe sleep recommendations to reduce SIDS, personal story of infant lost to SIDS, and advertising for a safe sleep product (Baby Box University)
+game,nfl,+player,+time,+season	1188 (8.84)	Football discussion that included information on daughter of a National Football League football player who died from SIDS
+risk,breastfeeding,+researcher,+study,+month	1004 (7.47)	Breastfeeding reduces SIDS (recent study on SIDS)
aidan,+loss,+cemetery,+child,remains	517 (3.85)	October as National Pregnancy and Infant Loss Awareness Month (personal stories of pregnancy and infant loss due to SIDS)
+swaddle,+sleep,+myth,unexplained,+sleep	488 (3.63)	Safe sleep recommendations to reduce SIDS and advertising for sleep products (Dr Harvey Karp's bed, baby hammock)
+baby,+pacifier,baby,mortality,+bed	337 (2.51)	Safe sleep recommendations to reduce SIDS and advertising for Baby Box University
+substance,+brain,+abnormality,+river,Adelaide	329 (2.45)	Australian study links brain chemicals to SIDS
finnbin,smartmom,safe,sleep,+school	315 (2.34)	Finnbin Box partners with Web-based mom group to increase safe sleep, and advertising for baby box, SafeSleepSchool.com
mata,+adoption,eac,violah,davises	277 (2.06)	Personal story of infant loss due to SIDS
drpaolini,and_kell,steffieschiltz,lilearthling369,markjarthur	241 (1.79)	United States and vaccines cause SIDS
+day care,broadway,+care,oregon,+facility	228 (1.70)	Baby dies from SIDS in Oregon at daycare

Table 3. Sudden infant death syndrome (SIDS) and safe sleep tweets by topic for November 2017.

Topic	n (%)	Description
â,+baby,+child,+sleep,+sleep	3063 (13.53)	Safe sleep recommendations to reduce SIDS, vaccines cause SIDS, advertising for infant sleep products (book on sleep, Sleep N Feed), and baby box initiatives (in Tennessee, Minnesota, and Colorado)
+vaccine,+cause,autism,+cancer,myonesciencetweet	1630 (7.20)	Explanation of SIDS (vaccines do not cause SIDS)
+smoke,tobacco,+smoke,secondhand,secondhand smoke	1595 (7.05)	Antitobacco information (includes statement that smoking increases SIDS)
breastfeeding,+study,+risk,+month,+researcher	1495 (6.60)	Breastfeeding reduces SIDS (recent study on SIDS)
gaither,+alcohol,+drug,+pregnancy,+birth	680 (3.00)	Risks of smoking and alcohol while pregnant (including risk of SIDS), Muslim habits versus that of the West (regarding behavior while pregnant and risk of SIDS), and high infant mortality rates in the United States (possibly due to SIDS)
step2,halo,snoozypod,carle,+giveaway	623 (2.75)	Halo SleepSack information, including advertisement and Web-based giveaway (founders lost infant to SIDS), personal recommendations on sleep, and how to prevent SIDS
+thermometer,shu,avery,+monitor,+technology	395 (1.74)	Report on health-monitoring technologies for babies to prevent SIDS
and_kell,kenjaques,vbalance03,badzoot7,drpaolini	224 (0.99)	Explanation for SIDS (vaccines do not cause SIDS)

Another theme identified was safe sleep devices. In November, safe sleep messaging included advertising for the following: Baby Box Co, Baby Box University, and a baby hammock. The concept of a baby box was also present in October, where 3 topics specifically discussed the concept of a baby box, Baby Box University, and Finnbin Box. In November, 2 topics were related to safe sleep devices; one topic included baby box initiatives, and advertising for the Halo SleepSack was also found. In November, an entire topic was dedicated to infant health-monitoring devices and SIDS.

A third theme identified was the potential cause of SIDS. In September, 5 of the topics were related to the causes of SIDS and identified the following as contributing to SIDS: vaccines, alteration in serotonin, and brainstem abnormality or cardiac-mediated SIDS. Within this category, however, it was also mentioned that vaccines do not cause SIDS. In October, 2 themes were related to the potential cause of SIDS: one was tweets calling out individuals and claiming that the United States and vaccines cause SIDS; the other was about an Australian study that found alterations in serotonin contributes to SIDS. Finally, in November, 2 of the topics included information on the cause of SIDS, including a transcript from an antivaccine conference where vaccines are claimed to cause SIDS, as well as a tweet stating vaccines do not cause SIDS.

The fourth theme identified was a recent study's findings that breastfeeding reduces SIDS. Additionally, the risk associated with smoking and alcohol use during pregnancy was a theme. Within this topic was a detailed comparison of Muslim habits versus those of the West with regards to smoking and alcohol use during pregnancy.

Finally, the month of October demonstrated 5 topics that detailed personal and specific stories of infant loss. These stories included those of a football player who lost an infant and a baby that died in an Oregon daycare from SIDS. This was expected as October is Pregnancy and Infant Loss Awareness Month [28].

Influencers and Reach

Data on top influencers for SIDS and safe sleep for the months of September, October, and November 2017 have presented in Tables 4-6, respectively.

The top influences were news organizations, universities, and health-related organizations, such as the Centers for Disease Control and Prevention and WebMD. One top influencer, The Australian, shared information about an Australian study linking brain chemicals to SIDS; this study's findings continued in its popularity throughout this analysis.

Another top influencer, ABS-CBN News, a Filipino news organization, posted about breastfeeding and reducing the risk of SIDS, while another top influencer, Forbes Health, later posted about formula not doubling the risk of SIDS. Likewise, other top influencers, WebMD, Today's Parent, and Norton Healthcare, posted about how breastfeeding reduced the risk of SIDS.

Thus, the topics posted by the top influencers primarily addressed the Australian research study linking brain chemicals to SIDS, risk factors for SIDS (alcohol use), and SIDS prevention (primarily discussing the importance of breastfeeding).

Table 4. Sudden infant death syndrome (SIDS) and safe sleep top influencers for September 2017.

Influencer	Posted description of the influencer	Number of followers	Post topic
The Australian, @australian	News from The Australian newspaper and The Australian Online.	644,471	Australian study linking brain chemicals to SIDS
United Nations Human Rights, @UNHumanRights	The United Nations #HumanRights office is led by High Commissioner #Zeid.	1,834,760	Unrelated topic, standing up for human rights
Uni of Adelaide, @UniofAdelaide	Official account with answers for your uni questions.	43,925	Australian study linking brain chemicals to SIDS
CDC_NCBDDD, @CDC_NCBDDD	CDC's Center protecting those most vulnerable to health risks: babies, children, people with blood disorders, and people living with disabilities.	6408	Alcohol use during pregnancy can also lead to miscarriage, stillbirth, and SIDS

Table 5. Sudden infant death syndrome (SIDS) and safe sleep top influencers for October 2017.

Influencer	Posted description of the influencer	Number of followers	Post topic
ABS-CBN News, @ABSCBNNews	Stories, video, and multimedia for Filipinos worldwide, from ABS-CBN News and Current Affairs, the Philippines' most trusted news organization.	5,588,990	Breastfeeding lowers risk of SIDS
Rutgers University, @RutgersU	Rutgers, The State University of New Jersey, is a leading public research university.	124,465	SIDS prevention
Tesco, @Tesco	Every little helps. Follow us for quick and easy recipes, food inspiration and helpful home hacks.	512,320	Unrelated topic (insect is pronounced "soh-sids")
The Advertiser, @theTiser	Breaking news and features from The Advertiser and Sunday Mail.	131,246	Australian study linking brain chemicals to SIDS

Table 6. Sudden infant death syndrome (SIDS) and safe sleep top influencers for November 2017.

Influencer	Posted description of the influencer	Number of followers	Post topic
Forbes Health, @ forbeshealth	@Forbes news covering the business of big pharma, health care and science.	74,653	Formula feeding does not double risk of SIDS
WebMD, @WebMD	WebMD and our medical team bring you the most trust-worthy and timely health news and information.	2,576,232	Study supporting breastfeeding reducing risk of SIDS
Today's Parent, @Todaysparent	"The days are long, but the years are short." Canada's #1 parenting brand.	2,526,850	Study supporting breastfeeding reducing risk of SIDS
Norton Healthcare, @Norton_Health	Official page. Caring for our community and tweeting because we believe #health should keep up life.	6390	Study supporting breastfeeding reducing risk of SIDS

Table 7. Trending hashtags (by order of occurrence and month).

Month	Trending hashtags
September	#sids, #vaccines, #unga, #hr36, #safesleep365, #autism, #vaxxed
October	#sids, #vaccines, #safesleep, #sidsawarenessmonth, #caboverde, #learntherisk, #uxnow
November	#myonesciencetweet, #thankyoursid, #sids, #cop23, #nottobacco, #280characters, #vaccines

The organizations with the most reach varied by month and included goodhealth, ABS-CBN News, and WebMD. These organizations shared the following messages: swaddling may put babies at risk for SIDS and breastfeeding reduces SIDS. Notably, there is no dominant social media voice related to this issue, with reach driven primarily by topical news stories.

Hashtags and Most Shared Mentions

The trending hashtags related to the topics have been presented in Table 7.

When comparing the trending hashtags, the topic of vaccines persisted throughout September, October, and November. For instance, "#vaccines" was the second most common hashtag in September and October. "#autism" came in as the sixth most common hashtag in September; this highlights the continued debate among the public regarding the possible link between vaccines and SIDS, as well as autism, despite public health efforts.

Furthermore, a marked variation existed among the most shared positive mentions, identifying the popularity of stories of personal loss as well as efforts of the AAP to educate the public on safe sleep and SIDS. In September, the most shared positive mention was a tweet from a host on NBC Sports with 25,367 followers, asking for donations to a friend who lost their 4-month old to SIDS. In October, the most shared positive mention was from HealthyChildren, the official parenting website of the AAP, with 39,082 followers, offering information about placing babies to sleep on their back as well information about SIDS and safe sleep environments. It is worth highlighting that this is the only mention of a safe sleep environment when reviewing the top influencers, those with the most reach, and the most shared positive mentions. The most shared negative mention of the keywords occurred in November, when Doc Bastard, with 16,508 followers tweeted "*Vaccines do not cause autism, SIDS, autoimmune disorders, diabetes, or cancer. They cause adults.*"

Discussion

Principal Findings

Analyzing social media to better understand a subset of the population's perceptions and exposure to information is a helpful and essential tool. This analysis of conversations surrounding the concepts of SIDS and safe sleep has helped identify major themes that otherwise would have persisted without acknowledgment from the medical or public health communities. In understanding the topics and themes that are popular on social media, health care and public health professionals can begin to address some of the common misconceptions and beliefs regarding SIDS and safe sleep. Furthermore, this analysis has been helpful in pointing out the general lack of public health agencies' presence on social media. With the information gained from this analysis, health care professionals and those in the public health arena can begin to have a more directed dialogue with the public and engage in more effective communication about this topic with the goal of ultimately reducing the incidence of SIDS due to unsafe sleep environments.

There is an opportunity for health care providers to engage in conversation with families about conflicting information they may be exposed to via social media, with the goal of providing accurate information. In this analysis, we identified themes that demonstrated conflicting statements that may be confusing for the average social media user. For instance, there is the mixed message of vaccines causing SIDS and vaccines not causing SIDS; this conflicting and contradicting finding is similar to what was found in an analysis of Twitter to better understand emerging topics and current vaccine perspectives [29]. In that analysis of Twitter data, there was an identified prevalence of negative sentiment surrounding vaccines as well as distrust toward organizations that deliver scientific evidence.

Furthermore, the general conflicting ideas among themes are consistent with the identification of confusion and misunderstanding that was found in a study attempting to better understand the misunderstanding regarding and misuse of antibiotics through a Twitter analysis [22]. Therefore, this identified theme provides an opportunity for health care and public health professionals to openly address this confusion and reassure families that vaccines do not cause SIDS.

Another area of opportunity was highlighted in October. There was markedly high Twitter activity in October, which was expected given that October was Pregnancy and Infant Loss Awareness Month [28]. However, this appeared to lend itself to more stories of personal loss rather than an increased public health presence to promote safe sleep awareness or SIDS prevention. Similarly, another study found that tragic deaths were highlighted rather than AAP guidelines for safe sleep reviewed in an analysis of websites to determine the accuracy of safe sleep [30]. Thus, health care professionals and public health agencies should respond by pairing personal stories of loss with recommendations for safe sleep and SIDS prevention. Because in October, there was an increase in the overall activity, but not specifically regarding safe sleep and SIDS prevention, this creates an opportunity for continued education and discussion of safe sleep recommendations originating from either health care professionals or public health agencies. As an example of outreach, researchers working in this area could coordinate with institutional communication offices to share and spread their work; such an approach is likely to have a substantial reach given the power of institutional press releases and communication channels in this analysis.

In addition, health care providers and public health agencies should address the amount of advertising noted in this analysis. For instance, much of the safe sleep recommendations and guidelines were embedded with advertising for safe sleep products. Some of these products follow and promote AAP guidelines for safe sleep, while others, such as the baby hammock, do not. The popularity of baby box initiatives and infant health-monitoring devices should also be recognized. This finding of incomplete congruence of safe sleep recommendations among advertised products is similar to prior findings of inaccurate safe sleep portrayed online [30]. Understanding the commonality of advertised safe sleep devices and infant health-monitoring devices is important so that practitioners can engage in more productive and effective communication with patients regarding the topic of SIDS and safe sleep behavior. Furthermore, public health agencies can address this issue by openly commenting on the lack of evidence to support many of these products, as well as the potential hazards associated with them.

Finally, public health campaigns and efforts should utilize university and news outlets to reach out to public for educational and more effective health communication regarding the topic of SIDS and safe sleep recommendations; this statement is based on the finding that the major influencers were noted to be universities and news media organizations. Furthermore, as previously mentioned, it is emphasized that public health organizations need to play a more active role in combating false information that is so readily shared via social media outlets; this sentiment is also shared by other researchers who have analyzed social media [21,22,31].

Limitations

When considering the implications of this work and directions for future research, it is necessary to recognize this study's limitations. Although the Twitter users have been profiled [19], the findings cannot be completely generalized to the American population. Therefore, the themes identified may only apply to a subset of the American population. Additionally, the validity of the postings on social media may not have been intended to be taken at face value and may include gross exaggerations. Thus, generalizing from these statements may not be a completely accurate reflection. Furthermore, top influencers were determined by the number of followers, mentions, and shares rather than the number of retweets. A different algorithm could potentially identify other top influencers and, thus, impact the findings of this analysis. Moreover, the time period during which the analysis was performed could impact the identified topics. Efforts were made to include September, October, and November to adequately capture the potential effects of October being Pregnancy and Infant Loss Awareness Month. However, a different time period may have resulted in different topics surrounding SIDS and safe sleep. Furthermore, analyzing 3 consecutive months does not control for carryover effect and may have impacted the identified monthly themes.

Conclusions

This study offers valuable information regarding what a subset of the American population believes and is exposed to with regards to SIDS and safe sleep. It highlights the contradicting information that the public is exposed to regarding SIDS and the continued controversy over vaccines. Furthermore, this analysis emphasizes the lack of public health organizations' presence on Twitter compared with the influence of universities and news media organizations. This study also demonstrates the prevalence of safe sleep products that are embedded in safe sleep messaging. Such findings can assist health care providers in speaking about relevant topics when engaging in conversations about the prevention of SIDS and promotion of safe sleep. Public health agencies and advocates should further utilize social media and Twitter to better communicate accurate health information as well as continue to combat the spread of false information.

Conflicts of Interest

None declared.

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Abbreviations

AAP: American Academy of Pediatrics
API: application programming interface
ASSB: accidental suffocation and strangulation in bed
HINTS: Health Information National Trends Survey
SIDS: sudden infant death syndrome

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Original Paper

Exploring Social Media Group Use Among Breastfeeding Mothers: Qualitative Analysis

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Abstract

Background: Breastfeeding is well known as the optimal source of nutrition for the first year of life. However, suboptimal exclusively breastfeeding rates in the United States are still prevalent. Given the extent of social media use and the accessibility of this type of peer-to-peer support, the role of social networking sites in enabling and supporting breastfeeding mothers needs to be further explored.

Objective: This study aimed to leverage mothers’ attitudes and behaviors of social media usage to understand effects on breastfeeding outcomes.

Methods: Participants were recruited from 1 probreastfeeding social media group with over 6300 members throughout the United States. Online focus group discussions were conducted with 21 women; interviews were conducted with 12 mothers. Qualitative data were aggregated for thematic analysis.

Results: Participants indicated that the social media group formed a community of support for breastfeeding, with normalizing breastfeeding, empowerment for breastfeeding, resource for breastfeeding, and shared experiences in breastfeeding as additional themes.

Conclusions: According to participants, social media groups can positively influence breastfeeding-related attitudes, knowledge, and behaviors as well as lead to longer duration of breastfeeding. The results of this study should be taken into account when designing interventions for breastfeeding mothers.

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KEYWORDS

social media; milk; human; breastfeeding

Introduction

Background

Major health organizations, including the American Academy of Pediatrics, World Health Organization, and Academy for Breastfeeding Medicine, recommend, at minimum, exclusively breastfeeding for the first 6 months of life, with continued breastfeeding for at least 1 year and thereafter as mutually desired by both mother and infant [1-3]. Although breastmilk has been well known as the optimal source of nutrition for infants for decades, research continues to accumulate on the benefits of breastfeeding for the mother-infant dyad, building an extensive scientific database of high-level research consisting of qualitative and quantitative studies.

According to the Centers for Disease Control and Preventions’ 2018 Breastfeeding Report Card, approximately 4 out of 5 (4/5, 83%) infants born in 2015 were ever breastfed, with rates increasing from previous years. In addition, an estimated 57.6% of infants were breastfed at 6 months. However, less than half of those infants (24.9%) were exclusively breastfed at 6 months [4]. Breastfeeding disparities exist for southeastern states, where breastfeeding initiation rates are as low as 63.2%, and 6-month breastfeeding exclusivity at a mere 13.0% for Mississippi. For southeastern states, the highest prevalence of breastfeeding at 6 months occurred in Georgia (55.5%), which is lower than the US national average [4]. Furthermore, Healthy People 2020 has specific Maternal, Infant, and Child Health objectives (MICH) for breastfeeding, with MICH-21.5's focus on breastfeeding exclusively through 6 months [5].

A recent, extensive meta-review of 28 systematic reviews and meta-analyses reasserted the most known and agreed upon effects of exclusively breastfeeding for the infant: lower infectious morbidity and mortality, higher intelligence than those who are formula fed, and protection against later-in-life development of overweight and diabetes, to name a few [1,6,7]. In addition to the direct benefits of exclusively breastfeeding for the infant, there are also benefits gained by the mother from exclusively breastfeeding, which include protection against breast cancer, delayed onset of ovulation, and reduction in both ovarian and breast cancer risk [6]. A recent cost-benefit analysis for breastfeeding estimated that the *scaling up* of breastfeeding could prevent 823,000 child deaths and 20,000 breast cancer deaths per year worldwide [6]. These benefits associated with breastfeeding are key components for health promotion and disease prevention for the mother-infant dyad [8-11], which is why it is important for women to be able to not only attempt breastfeeding but also be successful at it.

Access to social support during the perinatal and postpartum periods have been linked to better maternal health and child development outcomes as well as increased relationship satisfaction (for partner-to-partner as well as parent-child interactions) [12,13]. Conversely, lack of social support is often cited as a reason for breastfeeding cessation [14-17]. Peer support can come from family, friends, or even other mothers who are strangers [17,18], and this support can occur in-person or across virtual modalities [17,19,20]. A recent meta-analysis of social support interventions for breastfeeding mothers has shown to increase breastfeeding initiation by 86% and exclusive breastfeeding by 20% [21]. The US Preventive Services Task Force recommends peer support as 1 of the 3 recommended types (professional support and formal education being the other 2) during pregnancy and after birth to support breastfeeding [22].

In recent years, research around the juncture of motherhood and technology has grown significantly [13,23]. Social media outlets have been used to spread health-related messages as well as to provide a *forum* for those seeking health information. The main advantage of using social networking sites (SNSs) concerning health information is that they enable the widespread interaction of users as both receivers and providers of health information and knowledge [24]. Although the number of studies around social media use, social capital, and technology has increased, there is still much to be explored in this emerging realm—especially regarding MICH.

Objectives

The exponential growth of user-generated content embedded within SNS elicits a need for a further understanding of communication dynamics involved in these online forums [25]. Although numerous studies have provided a foundation for evidence of SNSs as community building and even stated the use of groups on Facebook as a pathway for community interaction [23], there is a lack of knowledge in the scientific community about how breastfeeding mothers influence other mothers online and how these influences impact mother's and infant's health outcomes. In addition, there exists (minimal, at best) research on how communication between breastfeeding mothers who use SNS supports breastfeeding. As it is well known that social relationships and support play a critical role in breastfeeding-related behaviors, social media usage is a topic of importance [26,27].

Furthermore, the use of virtual communities within SNSs for knowledge sharing is only recently being studied [28]. Individual's personal values can often serve as motivation for knowledge sharing in the absence of personal familiarity or assumptions of direct reciprocity, indicating social capital plays a significant role in knowledge contribution within the online realm [29]. Despite the growth in literature regarding knowledge sharing within SNS, current research on breastfeeding-related behaviors and outcomes within the realm of SNS is narrow, focusing on extrinsic motivators, already known benefits of breastfeeding, or familial or partner support. There exists immense opportunity for recently emerged technologies, such as social media groups on SNSs, to provide interaction, support, and information to breastfeeding mothers. However, to date, there exists very little information regarding breastfeeding mothers' use of social media groups and its impact on knowledge, attitudes, and behaviors. To address this gap, the proposed study aims to leverage mothers' attitudes and behaviors of social media usage to understand effects on breastfeeding outcomes.

The qualitative findings shared here are part of a mixed-methods study to comprehensively explore mothers' behaviors and attitudes of social media group usage toward the online platform as a means of increasing breastfeeding uptake. The goal of the qualitative phase of the study is to gain meaningful, in-depth insight into the mindset of mothers. The following research question guided the qualitative strand of the study: How does social media group usage support breastfeeding mothers?

Methods

Study Design and Setting

The results of the qualitative strand of this study were used to guide the development of a quantitative tool to assess breastfeeding mothers' social media group use and breastfeeding-related attitudes, knowledge, and outcomes. Participants were selected purposefully through a snowball sampling design. Women who were members of a Facebook probreastfeeding social media group were recruited via a post on the group wall in the fall of 2017. This group was selected because of the large number of members (>6300), their *probreastfeeding* approach (as designated by the title of the group), and accessibility to the group (US-based). This Facebook group originally stemmed from an in-person support group based at a mid-sized hospital in Birmingham, Alabama. However, there are no restrictions for joining the group: *any and all breastfeeding moms are welcome*, according to the Facebook group description. There are 5 *administrators* of the group, some of whom have International Board Certified Lactation Consultant (IBCLC) certification and others who do not have any professional training but are experienced in breastfeeding, either from feeding their children or from other experience (eg, work experience as a labor and delivery or neonatal intensive care unit nurse or from being a lactation counselor or dietician). Study participation was limited to women who were pregnant and intended to breastfeed, were currently breastfeeding, or who had recently weaned their infant in the past 3 years.

Study Participants

After screening for inclusion criteria, eligible participants were asked to participate in 1 of the 3 online focus group discussions (FGDs) or one-on-one interviews. Recruitment was conducted via wall posts within the group that asked mothers to participate in either a focus group or interview. Mothers who responded to recruitment posts were first asked to participate in focus groups. After focus groups were filled, respondents were then asked to participate in one-on-one interviews. All slots (as determined by when saturation would be achieved) were filled for both focus groups and interviews within 48 hours, so the post was then deleted. Of the 37 women recruited for online FGDs or interviews, all were eligible to participate. However, only 29 participants provided consent. A total of 21 participants participated in the online FGDs and 12 mothers participated in interviews; 4 mothers participated in both the online FGDs and interviews for validity purposes.

Data Collection

After informed consent was obtained, online FGD participants were randomized to either the first, second, or third online FGD. Participants were then added to a secret online group and asked to complete a demographic questionnaire before participating in the online FGDs. The online FGDs were asynchronous, and participants were given 4 days to read and respond to the initial post as well as to respond to and interact with others in the group. Detailed methodology, including reflection on the utilization of this methodology with mothers, is published elsewhere [30]. The intent of the interviews was to generate greater depth on themes brought up in the online FGDs. As such, the online FGD analysis guided the development of the interview instrument. The interview instrument was designed to be open-ended and to elicit thoughts, feelings, and experiences about social media use and breastfeeding (eg, How do you think the probreastfeeding group has impacted your breastfeeding relationship? What about the other social media groups?, Discuss a time that a social media breastfeeding group has impacted a decision or choice you made in regards to breastfeeding, What are some barriers or pitfalls to using social media to post or interact with other mothers about breastfeeding?, and How would you describe the information posted in probreastfeeding group in regards to accuracy?). This guide was developed to be comprehensive of themes derived from the online FGDs, but open-ended enough to allow interviewees to describe their experiences. All interviews were performed after informed consent was obtained and demographic questionnaires were completed. Participants were compensated with a US $10 Amazon gift card for their participation. Both online FGDs and interviews were conducted with the University of Alabama at Birmingham Institutional Review Board approval and oversight (REC300000306).

Data Analysis

Online FGDs and interview data were aggregated for analysis. The combined data transcript was then analyzed using Nvivo 10 (QSR International) for in-depth thematic analysis [31]. KRS coded the data and if she was unclear on a code, this was decided by the second coder. During initial coding, in-vivo coding was used for each phrase of the transcript, which was conducted by the researcher. The main reason for selecting an in vivo approach to coding was to stay *true* to the data, as this approach summarizes key phrases using participants' own words [32]. This approach is also advocated for within the framework approach for qualitative research analysis [32]. KRS also reviewed the coded data according to each theme and created a preliminary analysis results document to be shared with participants. This member checking was conducted to verify if the researchers' interpretation of the data was accurate. Themes were accepted by all 7 participants who were invited for member checking. The datasets generated and analyzed during this study are not publicly available as the authors do not have a website to publicly display them, but are available from the corresponding author on reasonable request.

Results

Demographics

At the time of enrollment, 2 women were currently pregnant (1 had previously breastfed and 1 was a first-time mother), 25 women were currently nursing, and 4 had weaned their child in the past 12 months. Other sociodemographic characteristics of participants are shown in Table 1.

Overall, 86% (25/29) of mothers selected their primary feeding method as exclusively breastfeeding (a mixture of at-breast feeds and breast milk bottles with no formula supplementation), with 16% (4/29) of these mothers feeding via at-breast feeds only and only 8% (2/29) exclusively pumping (infant only receives breastmilk from bottles). In total, 4 mothers reported ever providing supplementing formula; no infants were receiving formula supplementation at the time of the study. When asked how long they had been in the probreastfeeding social media group, most (18/29, 62%) had been in the group for more than 12 months, with 13% (4/29) and 34.% (10/29) being in the group between 6 and 12 months and less than 6 months, respectively. Interaction with the group varied: 75% (22/29) participants said they give advice and ask questions regularly within the group and 17% (5/29) stated that they do not interact regularly. For those who do not interact regularly, participants reported they searched in the group before posting or had recently weaned their infant as reasons why they were not currently active in the group.

Table 1. Demographic characteristics of online focus group discussions and one-on-one interview participants (N=29).

Demographic characteristics	Statistics
Age in years, mean (range)	29.7 (23-40)
Race, n (%)	
African American	3 (10)
American Indian	1 (3)
White	25 (86)
Education, n (%)	
High school diploma or some college	11 (38)
Bachelor’s degree (4 year)	10 (35)
Master’s degree	6 (21)
Professional degree (Juris Doctor and Doctor of Medicine)	1 (3)
Working status, n (%)	
Full- or part-time	25 (86)
Not working	4 (14)
Type of birth, n (%)	
Vaginal or vaginal birth after Cesarean	22 (76)
C-section	7 (24)
Infant ever admitted to neonatal intensive care unit, n (%)	0 (0)
Interaction with social media group, n (%)	
Ask questions	22 (76)
Give advice	22 (76)
Does not interact regularly	5 (17)

Participants’ attitudes, behaviors, and experiences with social media groups while breastfeeding were analyzed. The analysis resulted in 1 overarching theme of community, with the following supporting themes: (1) normalizing breastfeeding; (2) empowerment for breastfeeding; (3) resource for breastfeeding; and (4) shared experiences in breastfeeding. These themes are elaborated in detail below, providing quotes from participants for further harmonization and understanding.

Normalizing Breastfeeding

Mothers felt the group helped to combat stigma by normalizing breastfeeding, which emerged as a supporting theme. A large majority of posts were discussing how stigmatized breastfeeding still is, both on social media and in the real world. The stigma or fear of judgment extended beyond the realm of the public sphere and into the mothers’ families. Participants described the process as “isolating”:

> *Breastfeeding is still taboo in public. Sometimes our husbands or significant others or family members aren’t supportive.*

The theme of unsupportive friends and family members reigned throughout both online FGDs and one-on-one interviews:

> *Attitudes from friends and family definitely impacted my breastfeeding relationship. I felt unwanted a lot when visiting my in-laws and almost stopped nursing several times because of it. I feel like their attitudes also made me act unfairly towards my daughter. I often wouldn’t let her control how long the session lasted because I knew they would come and ask if we were done yet.*

Although a majority of mothers felt like their friends and family were not supportive of breastfeeding, a few reported that their friends and family were supportive:

> *I do however have one friend who has done nothing but encourage and support me. Her attitude helped me feel secure in my decisions until I decided to wean and she encouraged me to continue. She was still supportive when I went through with it though.*

Again, most participants felt that breastfeeding was still stigmatized, especially certain aspects of breastfeeding or how a mother chose to breastfeed (eg exclusively breastfeeding, exclusively pumping, or supplementing while breastfeeding). One participant commented:

> *A breastfeeding barrier that seem to be the most common for me is unsupportive people. Whether that’s from comments on social media posts on breastfeeding, a family member, or a stranger giving me the side eye while nursing in public.*

In addition to breastfeeding, mothers mentioned breastfeeding in public, exclusively pumping, continued breastfeeding (past 12 months), cosleeping, nursing at night, and supplementing while breastfeeding as all having their own *taboo*. As 1 participant stated:

> *Women are afraid of being shamed for breastfeeding. Whether it's for not being covered properly or the age of the child. I for one have experienced negative comments from some regarding nursing my 15 month old. Because of this, I don't readily advertise or discuss my breastfeeding relationship outside of the groups.*

It was discussed that within the group, most mothers felt like the group itself tried to normalize breastfeeding for mothers. This included expectations—what to expect at the beginning of the breastfeeding relationship, during the weaning process, and everything in between. The group was described as providing participants the opportunity to "understand what to expect and what's 'normal'" and "feel that, as with anything else in life, if expectations are properly set, everyone will be more satisfied with the experience." This information sharing generated positive outcomes within the mothers' experiences and overall approach of the activity:

> *It affects my attitude because it helps me know what to expect and, if I know what to expect and what's "normal," I am better able to accept what's going on. For example, knowing that cluster feeding is a normal thing, it didn't stress me out and cause frustration.*

Another mother stated:

> *Since there were so many other moms in the group, I felt like that [itself] made breastfeeding seem more normal, especially coming from a family where not one person has breastfed.*

Mothers felt like this normalizing within the group contributed to the success of their breastfeeding outcomes.

Empowerment for Breastfeeding

Almost all mothers also talked about the sense of empowerment they felt from the group. They discussed this in the form of confidence, empowerment, and support. For 1 mother, the group played a vital role in her breastfeeding relationship:

> *With my oldest son, I did not breastfeed at all so I knew nothing. However, I knew I wanted to breastfeed this time around, so I joined several breastfeeding groups to learn as much as I could. I felt very overwhelmed and scared, but after reading others' experiences and asking questions I felt much more confident. I wasn't sure how long we'd make it, but we are at 8 months and going strong!*

Mothers also discussed the high level of accountability in the group for encouraging one another. Some even stated that their breastfeeding duration or breastfeeding goals changed because of being in such a supportive and empowering environment. This was a common theme throughout both online FGDs and one-on-one interviews:

> *At the very beginning of my breastfeeding journey I was experiencing an extreme amount of pain. I wanted so badly to quit. The support I received from a social media group was invaluable. I was encouraged to never quit on a bad day. I never quit, because of the encouragement I got [from the group].*

Another topic brought up in many of the online FGDs and one-on-one interviews was nursing in public and the group's role in encouraging mothers to overcome this barrier. Many mothers talked about how supportive the social media group was for nursing in public, empowering and encouraging women to not be ashamed to feed their babies in public spaces, including parks, shopping centers, restaurants, and others' homes:

> *I am more willing to nurse in public than I would have been without being a part of these social media groups. I am very conservative but I now have nursed my son while shopping and speaking to a sales clerk-something I would never have dreamed of until I felt empowered by all of the ladies in these groups!*

Enhanced confidence was also brought up as a result of being in the group, going along with the theme of empowerment. From first-time mothers to experienced breast feeders, the majority of participants stated the group helped them to alleviate concerns or self-doubt they had regarding breastfeeding. Issues around having enough milk supply, supplementation of formula, use of prescription medication, and going back to work were all brought up in regards to maternal confidence. However, mothers reported that the social media group helped them feel empowered and confident about these issues after interacting with other members:

> *Largely because of what I was reading in [the social media group] I gained the confidence to allow my son to nurse on demand, as opposed to trying so desperately to adhere to a nursing schedule. I also decided to wait until a week or so before I go back to work to begin preparing my pumped stash. Outside of these two decisions, I have gained confidence and affirmation about the decision to nurse in general and guidance on so many questions/concerns/doubts I've had as a first-time mom.*

Resource

Mothers perceived the social media group to serve as a resource for breastfeeding mothers, providing real-time and accurate information for all things breastfeeding. Mothers in the study reported that just knowing the group existed to ask questions helped to alleviate their stress. Some mothers did not know any breastfeeding mothers, so the group served as a *pool* of potential mentor mothers to ask:

> *It benefitted me by having a resource for which I could ask literally any question under the sun related to breastfeeding, and I would have an answer and an explanation within hours, sometimes even within minutes. The ability to post on the group with questions and the peace of mind it gave me just knowing that it was there was very meaningful for me during my journey.*

This value of information was further enriched by the level of availability to mothers, unlimited by time or access restraints:

> *Posting on social media groups will benefit us by making solid researched information, as well as personal experience from other moms, readily accessible. With no mothers in my own family who breastfed, the number of women to whom I can ask questions is very limited. Social media broadens that pool.*

Mothers reported that the group was helpful at all hours of the day and night, where people could receive *real-time* answers. The real-time answers mothers reported to be helpful for sustaining their breastfeeding relationship covered a variety of topics and issues, stating:

> *I was really concerned about how much pumped milk to leave my baby when I returned to work. People flooded me with knowledge and charts to help calm my fears and helping my return to work become easier.*

The social media group was reported to be a place of support and comfort when mothers did not know what to do or where to turn. This is prevalent throughout the data, but mothers discussed how after interacting with the group (through seeking advice, reading previous posts, or just interaction) their breastfeeding outcomes were positively impacted:

> *Well, when my child was going through his first growth spurt, he ate every single hour through the night. The next morning my mother-in-law expressed concern that my milk production was low or not keeping him full and asked if I wanted to supplement formula. Without the groups I'm in, I probably would've supplemented but because I could post and ask what to do, I found out it was completely normal and now we are on week 11 of breastfeeding.*

This experience was common among participants, with outcomes stretching from basic nutrition to practical matters:

> *The [social media] group influenced me to still nurse as much as possible when our pediatrician recommended supplementing, they helped me know when my baby was gaining enough weight, they helped me decide how many times to pump at work, how many and what size bottles to send to daycare, etc.! I have learned so much!*

Shared Experiences

A common theme brought up was 1 aspect of the group mothers really appreciated—shared experiences. Mothers discussed they felt more trusting and able to understand the advice given within the group, as it came from other breastfeeding mothers. These mothers had gone through the same struggles and triumphs as others and were able to impart their knowledge onto others who were experiencing a similar situation:

> *These groups help me make decisions based on hearing experiences from a large group of women. As mothers, we are constantly questing ourselves because we do not want to mess up our children. These groups help me learn from others so that I can avoid some practices that might not be as effective as others.*

Also reported in the online FGDs and one-on-one interviews was that mothers knew the value of having access to people with shared experiences. Most reported they did not know other mothers who were breastfeeding or had previously breastfed, so having the ability to ask advice and seek help from those who had gone through the experience in the group was a critical component of their successful breastfeeding relationship. Mothers discussed that they felt the shared experiences of others both comforting and empowering at the same time, stressing that "Nothing replaces training like experience. And doctors, and nurses, receive so little training in breastfeeding. Having the group as a resource is amazing" as well as simply "realizing I am not alone, in both the struggles and successes."

Others felt the social media groups helped them to feel more empathy and compassion for other mothers. Through shared experiences and shared struggles during the breastfeeding journey, mothers felt they were able to connect with other mothers:

> *I feel like I'm able to be more compassionate and have more empathy toward all moms, because, through stories on the group page, I learned about moms dealing with multiple bouts of mastitis, baby biting, thrush, blebs and blisters, low pump supply, etc. Because I never experienced those things first hand, I feel like I wouldn't be as understanding toward others having difficulty because I didn't know it could be so hard for some.*

Community

The 1 overarching theme discussed in the online FGDs was *community*. Participants felt like the probreastfeeding social media group was a place where they felt a bond with other mothers and where they were understood. Some participants noted the group brought strangers together around 1 topic and united them. Participants described their relationship with the group as being "always nice to have a place to go where you are 'understood'" as well as appreciating the group's ability to "normalize not only breastfeeding but also the troubles that surround breastfeeding moms. It brings us together!"

Participants also brought up a strong sense of confidentiality within the community and current members of the community. They felt a strong sense of trust and nonjudgment from a group composed predominantly of strangers. However, participants said they would be hesitant to seek advice or help from the group if they had people they knew within the group. Coworkers, family, and even close friends were mentioned by participants within this context. As 1 participant shared:

> *I would be much less inclined to seek help from the group if I had coworkers that were also group members. I could see myself being too embarrassed to ask for help from people who know me, simply as a matter of pride.*

A large portion of the discussion for both online FGDs and individual interviews integrated the trust and confidentiality within the social media group, indicating that these types of groups may be a rich place for knowledge sharing.

Discussion

Principal Findings

The sense of community and shared experience as well as overall support in the breastfeeding practice were major themes that emerged. Furthermore, findings from this qualitative study elicit the notion that certain probreastfeeding social media groups could be considered a pillar of support for breastfeeding mothers, which is consistent with findings that mothers seek support for breastfeeding through a variety of channels [12,16,17,33]. These channels include in-person support groups, mobile apps, and online forums. Online support mechanisms, including mobile apps and social media, have only recently been explored for utilization during the postpartum periods [34,19,35], and even more recently for breastfeeding support [16,19,20]. As such, there is miniscule information on how social media groups support breastfeeding mothers; these results and findings shed light on topics not previously covered through traditional *mothering* groups and bring up novel areas for providing support to breastfeeding mothers.

Another main theme discussed in the online FGDs and interviews was normalizing breastfeeding. This included discussions on how the probreastfeeding social media group tried to iterate the normalcy of breastfeeding in public, exclusively pumping, continued breastfeeding, cobreast sleeping, and night nursing, to name a few. Participants brought up the fact that they often felt stigmatized within the real world in regard to breastfeeding, but did not feel any stigma within the social media group. Although literature has shown that the stigma associated with breastfeeding in public has been associated with lower breastfeeding rates, our results show that the mothers within this social media group empower one another to overcome their fears and tackle nursing in public *breast-on* [36]. Although most mothers reported not knowing what to expect during the breastfeeding journey, almost all participants said the group helped to define realistic expectations and what *normal* means for breastfeeding mothers. Along with helping to establish and maintain expectations, this social media group was found to help *normalize* breastfeeding, having a profoundly positive impact on the breastfeeding journey.

Organically brought up by mothers was the sense of empowerment for breastfeeding they received from their interaction with the social media probreastfeeding group. This empowerment came to fruition in the form of confidence, empowerment, and generalized support for breastfeeding. There was a very high level of support and trust within this social media group, which led mothers to discussing more personal and sensitive topics—disclosing they shared more personal information within the group than they shared with their pediatricians or obstetricians. Mothers reported having access to, being able to interact with, and ask questions to those who had already gone through the same struggles and triumphs during the breastfeeding relationship was an incredible asset within the probreastfeeding social media group. This led to mothers disclosing they trusted other mothers' advice within the probreastfeeding social media group more than they trusted their pediatricians' or obstetricians' breastfeeding-related advice. Pediatricians are not known as *experts* for breastfeeding; there are others (eg, IBCLCs, lactation consultants, and registered dieticians) who have extensive training and certifications to assist breastfeeding mothers. With the existence of these experts becoming more well known, it is not surprising that mothers are not trusting their pediatricians for breastfeeding advice. This also touches on the theme of peer support, which has been shown to help breastfeeding outcomes [12,16,22,33]. From mothers' discussions of their interactions, it became clear that access to other breastfeeding mothers was a key supporting factor for the mother-infant dyad. It was also reported that through this interaction, mothers became more empathic and compassionate toward other breastfeeding mothers, reporting they were able to connect more with others, both inside and outside the social media group. This shows the importance of dynamic relationships and peer support throughout the breastfeeding process, especially for the formation of trust, which can help mothers adopt breastfeeding recommendations.

Social media groups, in general, were found to be a resource for breastfeeding mothers. However, mothers felt the degree of accuracy of information varied among social media groups. When mothers discussed the *probreastfeeding* social media group, they elaborated on not only the reliability of the information but also on how much they loved having access to *real-time* information. For example, mothers were able to ask a question at 2 am and get an almost immediate response from another breastfeeding mother who was up. Mothers reported this *real-time* resource as being invaluable to them—rather than having to search multiple websites for a specific answer or wait until a pediatrician or obstetrician visit, mothers were able to get fast and valid information from a variety of people—including IBCLCs and mothers who had already experienced the issue. It is critical to discuss the rapport of the social media group when discussing social media groups as a resource for breastfeeding mothers, as this can lead to trust or distrust among the members. Findings from other studies show that online support can be helpful for not only parenting [27,37] but specifically for breastfeeding [19,37].

In a broader context, it is important to bring up the distinct differences brought up between *mom groups* or *mothering groups* and *probreastfeeding groups* within the realm of social media, as this was also brought up in the group. There exist both *mothering* and *parenting* groups, where all parenting-related questions can be asked (eg, teething, formula feeding, and sleep training). The social media group used for this study was a *probreastfeeding* group, by self-indication. Administrators deterred other topics unless they were related to breastfeeding. There were breastfeeding experts in this group as well as other mothers who had successfully breastfed, creating somewhat of a natural community of practice. Mothers reported the probreastfeeding social media group being known for its strong and accurate advice, whereas other broader groups were designated as proformula and shamed breastfeeding mothers. Although most women had positive experiences with social media groups, not all experiences were positive, and there exists great variability in the ability of a group to support breastfeeding. This may shed light on the importance of alignment to group values as a necessary ingredient for or predictor of positive experiences and support for breastfeeding within the social media group. Furthermore, this shows the need for social media groups that are dedicated to different parenting topics such as breastfeeding or nutrition.

Although this study has discussed breastfeeding mothers' perceptions on the role of a *probreastfeeding* social media group for breastfeeding support, it is by no means exhaustive of all social media groups or of all breastfeeding mothers. However, now that qualitative data have been explored and it is known that social media groups could positively influence breastfeeding attitudes, opportunities to further explore this topic are immense. One area not explored in this study is unintended consequences of these types of social media groups. As this was a cross-sectional design, it is not best to answer this type of question. Future research should explore unintended consequences in a holistic manner. It is clear that there is a need for future research to design and implement interventions using social media groups in breastfeeding mothers to see if associations with standard breastfeeding outcomes exist. Future research should focus on the utilization of social media groups as a way to reach breastfeeding mothers from a clinical setting (ie, hospitals, lactation consultants, and postpartum support groups). As telemedicine has arisen in recent years, one cannot help but wonder if a model of care for breastfeeding mothers using peer support in a social media group format can be designed, implemented, and tested for efficacy. It is imperative to support breastfeeding mothers throughout the duration of the breastfeeding relationship; social media groups show promise as an effective way to do so.

There are many strengths of this study, including the participation of breastfeeding mothers, who can be a hard-to-reach or sensitive population; the innovation approach using online FGDs; and the uniqueness of the study phenomenon. Deggs and Woodyatt have published the strengths and opportunities of online FGDs, along with others [38-42]. Furthermore, the utilization of this methodology for this study is available online for review, which describes recommendations for including mothers in qualitative studies to yield rich data [30]. As mentioned, this study shines light on the use of social media groups as a tool for supporting breastfeeding mothers. However, although there are numerous strengths to this approach, there are also limitations to this study that must be considered.

Limitations

As this was an exploratory study with a small qualitative sample from a group of mothers located mainly in the southeast, the results may not be generalizable to all breastfeeding mothers who use social media. The smaller sample size was intentional, as qualitative studies are usually small in number because of their in-depth nature. However, there are some sociodemographic characteristics of this sample, which limit the generalizability of the study. These include a higher-than-average college education rate (30% have a master's or professional degree) and a high white percentage (86%). In addition, as online FGDs and one-on-one interviews rely on the individuals' perceptions and experiences of social media use and breastfeeding, these perceptions are dependent on sample selection. For mothers who were not currently breastfeeding, their reflection about the social media group was retrospective, the content of the social media group could have influenced them differently, which is another limitation to the study.

Conclusions

Our study shows that social media can positively influence breastfeeding related attitudes, knowledge, and behavior. The overarching theme of community reigned in this research, with a strong emphasis on social media groups as a way to normalize breastfeeding, to empower breastfeeding mothers, to serve as a resource for women, and to share experiences related to breastfeeding. Although findings from this study are novel to the field, they reflect broader studies that identify social media as a way to reach mothers and impact their parenting-related attitudes, beliefs, and behaviors [17,20,35,37]. Furthermore, this study specifically addresses a gap in the literature on how social media can influence infant-feeding practices and, specifically, breastfeeding [20]. In general, interaction with the social media group was reported to have a positive impact on the breastfeeding journey by way of all the main themes. As this study shows social media can have a profound impact on breastfeeding mothers in a positive way, ways to catalyze a shift in the way women receive health information must be jump-started. Future research should focus on how health care professionals and organizations can use social media groups to positively influence breastfeeding attitudes, knowledge, and behaviors to increase exclusively breastfeeding duration and decrease barriers or stigmas associated with breastfeeding, leading to better quality of life for mother-infant dyads, including both physical and mental health outcomes.

Authors' Contributions

KRS researched literature and conceived the study. KRS, RE, and JL were involved in protocol development, gaining ethical approval, participant recruitment, and data analysis. KRS was the moderator, interviewer, and completed all data analysis. KRS wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

FGD: focus group discussions
IBCLC: International Board Certified Lactation Consultant
MICH: maternal, infant, and child health
SNS: social networking sites

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Original Paper

Exploring the Transition to Fatherhood: Feasibility Study Using Social Media and Machine Learning

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Abstract

Background: Fathers' experiences across the transition to parenthood are underreported in the literature. Social media offers the potential to capture fathers' experiences in real time and at scale while also removing the barriers that fathers typically face in participating in research and clinical care.

Objective: This study aimed to assess the feasibility of using social media data to map the discussion topics of fathers across the fatherhood transition.

Methods: Discussion threads from two Web-based parenting communities, r/Daddit and r/PreDaddit from the social media platform Reddit, were collected over a 2-week period, resulting in 1980 discussion threads contributed to by 5853 unique users. An unsupervised machine learning algorithm was then implemented to group discussion threads into topics within each community and across a combined collection of all discussion threads.

Results: Results demonstrated that men use Web-based communities to share the joys and challenges of the fatherhood experience. Minimal overlap in discussions was found between the 2 communities, indicating that distinct conversations are held on each forum. A range of social support techniques was demonstrated, with conversations characterized by encouragement, humor, and experience-based advice.

Conclusions: This study demonstrates that rich data on fathers' experiences can be sourced from social media and analyzed rapidly using automated techniques, providing an additional tool for researchers exploring fatherhood.

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KEYWORDS
parenting; perinatal care; fathers; social media; parent-child relations; infodemiology; unsupervised machine learning

Introduction

Background

The transition to parenthood is a critical period for fathers and their families alike. The changing role from individual to partner to parent across the prenatal, perinatal, and postnatal periods requires men to undergo significant psychological transition [1]. The social and emotional changes that expectant fathers experience across the perinatal period are associated with increased risk of mental ill health in fathers [1,2]. An estimated 1 in 10 fathers experience depression across the perinatal period, and a further 2.4% to 18% of fathers may experience anxiety disorders [2,3]. The impact of poor mental health in fathers across the fatherhood transition can affect the entire family, with implications for the mental health of mothers and their combined parenting relationship [4] as well as implications for the development and well-being of children [5].

Despite the importance of parenting transitions for the well-being of fathers and their families, research exploring this topic is limited. Reviews to date have repeatedly noted the paucity of research available for synthesis [1,6,7], particularly when compared with studies exploring the transition to motherhood [1,2]. A key reason for the underreporting of fathers' experiences in the literature is the difficulty in reaching and engaging fathers in health research and practice [8,9]. Reasons for this difficulty reported in the literature include the perceived disinterest of fathers, the reluctance of mothers to involve fathers in perinatal care, stereotypes of men being incompetent or absent when it comes to caregiving, and fathers' own lack of help seeking [9,10].

Furthermore, research that does explore fatherhood transitions is typically limited by a number of methodological issues, as identified by a recent systematic review [6]. First, much of the research exploring fathers' transitions relies on mothers' reports of fathers' experiences rather than direct assessment of fathers themselves, with the validity of mothers' reports questionable [11,12]. Second, data collection periods typically capture fathers' experiences from the birth of their child onward, failing to capture fathers' prenatal experiences. Furthermore, research is typically focused on fathers' role in the marital relationship, despite transitions to parenthood being conceptualized as a complex, multidimensional process. Finally, research is typically completed using small sample sizes, assumedly because of the difficulty in recruitment and retention of fathers in research and practical limitations of the qualitative research methods typically employed. These difficulties in adequately capturing fathers' experiences might have flow-on effects into treatment services, where fathers are reportedly difficult to engage and treatments are likely to be ineffective [9].

Such methodological difficulties highlight the need for innovation in the way we engage men in research exploring their transition to parenthood. One promising area is through social media. Social media platforms offer an opportunity for researchers to passively track the health and well-being of the public at scale, regardless of their geographic location [13]. The natural formation of group discussions on social media offers researchers the opportunity to observe ecologically valid models of social support processes. It also offers the ability for researchers to capture rare in-the-moment data when people are experiencing an event rather than relying on their retrospective reporting (eg, via surveys or interviews).

Social media is a particularly promising avenue for fatherhood research. Although fathers are difficult to engage through traditional support settings, evidence suggests that electronic health strategies might be a more effective avenue at reaching and engaging fathers [14,15]. Fathers themselves report using the internet as a key source of information about pregnancy, childbirth, and postnatal care [16], and social media is used by fathers particularly for social support regarding their fatherhood role [17]. Research on fathers using social media has explored topics such as health care parental support [8], young fathers' experiences (fathers aged under 22 years) [18], the nature of social support provided through social media to fathers [19,20], and differences in the parenting roles of mothers and fathers [21].

Very little research has examined the feasibility of using social media data to explore fatherhood transitions specifically. A study by StGeorge and Fletcher [19,22] examined discussions between 23 current and expectant fathers in an Australian online forum over an 18-month period. Discussions converged onto 4 overarching themes: fathers' feelings of isolation because of the low support fathers receive, fathers' practices in balancing work and family life, social opinions on parenting issues such as breastfeeding, and announcements such as birth announcements and physical meet-ups. Although this study demonstrated that fathers are willing to discuss their experiences of the transition to fatherhood with other fathers on the Web, further research is needed to examine whether these results are generalizable to fathers' discussions on larger social media forums, with more diverse groups of fathers.

More recently, new techniques such as machine learning have emerged to explore social media data at scale. Machine learning refers to a subset of artificial intelligence algorithms that learn and increase in performance as new data are analyzed [23]. There are 3 primary types of machine learning techniques: supervised learning, in which data with known labels are used to create predictive models; unsupervised learning, in which mathematical techniques are used to cluster and distinguish patterns from uncategorized data; and semisupervised learning, in which both labeled and unlabeled datasets are used to make predictions. Machine learning has already been applied to many areas of parenting on social media such as predicting postpartum depression from Facebook posts [24] and analyzing vaccination discussions on mother forums [25]. Within the fatherhood space, Ammari et al [21] explored the influence of gender on parental roles by applying machine learning to both mother and father discussion forums. Using Latent Dirichlet Allocation (an unsupervised machine learning technique), the authors found that machine learning was useful for mapping parenting discussions on social media. This study demonstrates that fathers are very active on social media sites (specifically the Reddit platform), offering the opportunity for new research avenues and additional machine learning techniques to be explored with fatherhood discussions on social media.

Objectives

This study, therefore, aimed to assess the feasibility of using social media data to explore changes in the discussion topics as men transition to fatherhood. Specifically, we aimed to map the discussion topics held between both expectant and current fathers on the international forum *Reddit*. We expected to observe fathers discussing similar issues to that reported in previous research, such as work-family life balance, parenting practices, and difficulties engaging with health professionals, within a framework of positive social support. We then aimed to compare and contrast these discussions between expectant and current fathers, expecting to find overlapping topics such as support and issues with spouses, sleep difficulties, and fatherhood anxiety.

Methods

Datasets

We explored topics of discussion from two publicly accessible Web-based parenting communities within the Web forum Reddit. As of April 2018, Reddit is the fifth most popular website in the United States (18th globally), with an average of 274 million unique users per month [26]. Users are typically college-educated males from the United States, aged under 35 years [26,27]. Reddit users can create forums based on topics of interest (called subreddits) to share and discuss related content with other users who subscribe to their own topics of interest to form special interest communities. Communities are self-moderated using an in-built voting system; *upvotes* increase a post's visibility, whereas *downvotes* decrease a post's visibility. Posts (ie, top-level discussion topics or individual comments in a discussion thread) are generated a total score by subtracting downvotes from upvotes.

There are several distinct subreddits that focus on parenting within Reddit, including r/Parenting (for general discussions on parenting), r/SingleParents (specifically for single parents), and r/Mommit (a place for mothers to discuss parenting). As the motivation of this study was to explore issues in the transition to fatherhood, we focused specifically on the 2 most popular subreddits for fatherhood, including r/Daddit (79,019 subscribers as of April 2018) and r/PreDaddit (17,923 subscribers as of April 2018), which are targeted to new fathers during pregnancy. Using the Reddit application programming interface (the official set of tools that provide third-party software with access to Reddit data), we first downloaded the most recent discussion threads (eg, original posts and their associated comments combined) from both of these subreddits, which are limited to a total of the most 1000 recent posts per subreddit. We then continued to automatically collect all new discussion threads from both of these subreddits over the proceeding 2-week period (March 23, 2018, to April 06, 2018). We also collected additional metadata, including post and comment scores (as voted by users), and anonymous user IDs to track participation across both subreddits by individual users.

Analysis

Several steps were taken to prepare the data for analysis using the Python Natural Language Toolkit (version 3.2.5) and scikit-learn (version 0.19.1). First, original posts and associated comments were grouped together to form single documents for analysis. We then cleaned the data by removing punctuation, stop words, and low- and high-frequency terms, followed by stemming (reducing words with similar meanings to their base form) and tokenization (splitting the posts into individual words while removing most punctuation). Documents with less than 50 total characters remaining were then removed to help improve algorithm accuracy. Finally, each document was vectorized (converting the text-based documents to numerical vectors) using term frequency-inverse document frequency (a method that weighs each word in a document based on the number of times it appears, offset by the number of documents in which that word appears).

Topic modeling was then performed using the machine learning algorithm *k*-means clustering. The *k*-means clustering technique is a widely used unsupervised clustering algorithm that can create clusters of documents that are similar to one another and dissimilar from the documents that are in other clusters [28]. One of the primary benefits of clustering techniques is that they are exploratory in nature, in the sense that they do not use predefined labels to group data [28]. We used the *k*-means clustering algorithm in sci-kit learn to analyze the discussion content from both subreddits as well as a combined corpus (the entire collection of posts). The clustering was performed for different values of *k* ranging from 5 to 15. After manually analyzing the results of clustering on each value of *k*, we settled on 9 clusters as the best value to represent the distinct discussion topics for each subreddit and the combined corpus.

We then further grouped the 9 discussion topics into broader emergent categories by using an open coding process as follows. First, the posts within each discussion topic were sorted by proximity to the center of the cluster, as more central posts best represent the features used by the algorithm to cluster the topic. Next, posts were sorted by user score to determine which posts were most important to the community. For both sorting methods, the authors independently read the posts in order and proposed a category theme. Discrepancies were discussed, and categories were revised until both authors agreed that the category label described the primary themes. As the primary aim of this study was to assess the feasibility of machine learning to map discussion topics of parenting in social media data, we chose to focus on simply labeling the topics rather than providing nuanced analysis on discussion content.

Finally, to compare the similarity and diversity of each topic between groups, Jaccard similarity coefficients were calculated. The Jaccard similarity coefficient is a common technique used to compare similarity and diversity of sets [29]. It is calculated by dividing the intersection of 2 sets by their union and multiplying the result by 100 to obtain a score. A score of 0 indicates that there is a large amount of diversity and difference between 2 topics, whereas a score closer to 1 indicates that these topics contain more similar words.

Results are presented by first mapping discussion topics across the fatherhood transition (ie, using both the r/PreDaddit and r/Daddit forums), then mapping the discussions of expectant and current fathers separately, and finally by comparing the discussions of expectant and current fathers.

Ethics in Data Collection on Social Media

Although the public nature of social media forums such as Reddit means that formal human research ethics approval is not required to use the data, there are other important ethical considerations that should be adhered to. Previous research has indicated that although contributors to public forums acknowledge a certain degree of open access, they still may not post with the intention of public visibility and still seek privacy where possible, for example, by using pseudonyms [30]. In comparison with social media networks such as Facebook and Twitter, which are linked to the true identity of each user, members of Reddit typically select pseudonymous usernames. Due to the nature of discussion topics (eg, topics on children), we deidentified any comments that included names and places.

Results

Discussion Topics Across the Fatherhood Transition

The final cleaned dataset resulted in 1980 discussion threads, which were contributed to by 5655 unique users, totaling over

765,000 words across a 6-month period (November 12, 2017, to April 06, 2018). The 9 discussion topics were grouped within 3 emergent categories: (1) Expectant Fathers' Milestones, including *Pregnancy Milestones*, *Birth Announcements*, and *First-time Fathers*; (2) Fathers' Practices, including the topics of *Growing Up*, *Cute Pictures*, and *Paternal Bonding*; and (3) Fatherhood Challenges, covering the topics *Struggles*, *Budgets and Purchases*, and *Sleep*.

Table 1 displays the descriptive statistics of each discussion topic. Overall, the Struggles discussion topic contained the largest number of posts, with 436 discussion threads and 4380 replies contributed by 2702 users. Unsurprisingly, the Struggles discussion topic also achieved the highest total user score (the combined score of all posts within the topic, as voted by users). The smallest discussion topic was Birth Announcements, which contained 57 discussion threads with 255 replies, contributed by 250 users.

Expectant Fathers' Milestones

The first emergent category, Expectant Fathers' Milestones, captured expectant and new fathers' experiences across the perinatal period. Most of the discussions across the category were celebrations of major events and milestones, such as *graduating* to fatherhood, with replies of encouragement and congratulations from the wider community:

Original post:

> *Graduated! Baby finally showed up 8 days late and 34 hours of labor from my rock star wife. 7lbs 10oz!*

Reply:

> *Currently in the hospital at 5 min contractions we are 2 days past due date so hoping this is it!!! Congrats man!* [Birth Announcement]

The community also helped to bring greater awareness of the challenges involved in the perinatal period, particularly around difficulties in conceiving and carrying the infant to term, for example:

> *Miscarriages are actually quite common. They just are not talked about much. I wish people would talk about them more to help other people. My wife had an ectopic pregnancy and lost one of her tubes. Since then, we now have an almost 4yo and a 6mo. A friend of ours had 3 miscarriages before a successful pregnancy. Good luck [original poster], and let the rollercoaster ride begin!* [Pregnancy Milestones]

The experiences of first-time fathers were particularly supported by the community, with posts in this category receiving an average score of 1702 (calculated by dividing the total user score of the category by the number of individual posts in the category). First-time father discussions were characterized by support and humor, for example:

Original post:

> *Today I learned to be a dad for the first time.*

Reply 1:

> *Being dad is a lifelong lesson, may you always be open to learning. Enjoy the adventure dad!*

Reply 2:

> *Nah, you just read the jacket cover and got excited about what comes next. Wait until you get to Chapter One, "Oh my God the poop has started to smell." The real good reads are the chapters "I was just pee'd on" and "I think I got throw up in my mouth." Don't buy the Cliff Notes. Congratulations on spending the rest of your life trying to hide the fact that you have no idea what your doing from your little one. You're one of us now.* [First-time Fathers]

Table 1. Emergent categories in the discussion topics of fathers across the fatherhood transition.

Topic	Discussion threads, n	Replies, n	Total user score	Word count
Expectant Fathers' Milestones				
Pregnancy milestones (users: n=740)	235	1078	13,292	51,916
Birth announcement (n=250)	57	255	6086	3754
First-time fathers (n=803)	152	945	25,876	12,414
Fathers' Practices				
Growing up (n=1856)	446	2474	45,920	1,31,526
Cute pictures (n=1040)	316	1074	29,865	26,667
Paternal bonding (n=831)	133	871	28,486	16,799
Fatherhood Challenges				
Struggles (n=2702)	436	4380	57,976	4,31,415
Budgets and purchases (n=503)	123	615	3490	61,126
Sleep (n=444)	82	470	7867	29,651

Fathers' Practices

While Expectant Fathers' Milestones focused on perinatal experiences, Fathers' Practices instead captured fathers' discussions on activities and feelings across their child's early development. The *Cute Pictures* topic involved fathers' sharing photos of their children and family with humorous captions, for example:

> *This one just turned 6 months, and is now pulling herself up and crushing furniture, trying to walk. She wants to chase her big sister around. She's gonna kill me. At least she's cute!* [Cute pictures]

The *Growing Up* topic included milestones in children's development as well as sharing stories of children's growing hobbies, interests, and personalities. As with other topics, fathers' responses were characterized by sharing their own similar experiences and humor, for example:

Original post:

> *Just need the support. I am out of town for work, and I missed my sons first word. He said "hi" to my wife...*

Reply:

> *That sucks! There'll be many firsts. This one feels big, but the fact you weren't present doesn't mean you're doing a bad job. Chin up. I got a first yesterday: first time he's said "i don't love you, dada!"* [Growing up]

Finally, the Paternal Bonding topic included discussions where fathers shared stories and photos of activities between themselves and their children, the emotions they felt about their relationship with their child, and their feelings about being a father more generally, for example:

> *Entered our car in the race yesterday with a lack of high hopes. 2nd place out of 65!!!! my son [the child] (7) was so happy he cried. I feel like I did something right!* [Paternal Bonding]

Fatherhood Challenges

The final semantic category that emerged from the combined discussions of expectant and current fathers was Fatherhood Challenges. This category included discussions on fathers' *Struggles*, *Budgets and Purchases*, and *Sleep*.

The topic *Struggles* covered a variety of difficulties that fathers were facing, with fathers also seeking support from their Reddit community. Examples of discussion thread topics included coping with children's diagnoses of serious medical conditions; difficulties in adapting to the *father* role; difficulties in relationships with partners and coparents; struggles with depression, anxiety, and other mental health conditions; and dealing with the loss of an infant. The community was strongly supportive of posts within the *Struggles* category, with the average post receiving approximately 10 replies, for example:

> *To all the Dads to be that are struggling; coming to grips with being a parent, dealing with an unreasonable hormonal partner, struggling to be loyal when not having your needs met, or even considered, struggling post-partum, remember, one day your kid will look at you and smile. Hang in there.* [Struggles]

Budgets and Purchases covered discussions about the cost of items, whether the items were necessary, and recommendations for products. Discussions were typically focused on expectant fathers and new fathers asking for recommendations and advice about the etiquette of baby shower registries and products for infants, particularly car seats and strollers, for example:

Original post:

> *Cheap vs Expensive baby stuff: whats the actual difference? [...] Just trying to wrap my head around how to research and select. [...]. its not that i cant afford it, its that I'd rather save the money and put the rest into funds for future expensive events like college. and food.*

Reply:

> *This is a great question. I have no idea how to shop for anything either, so thank you for asking this!* [Budgets and Purchases]

The topic of sleep emerged as a distinct discussion topic across the combined fatherhood transition. Discussions focused on fathers' struggles with their own sleep quality and fatigue, issues in helping infants and young children with sleep, and queries about sleep routines. Importantly, fathers typically recognized that sleep disturbances were a normal part of life after the birth of a child, for example:

> *3 days in from the birth of my little girl. Sleep has become a thing of the past now. Had my little princess on my chest since two in the morning to allow my wife to sleep. Just. So. Tired. But my little girl is just so perfect.* [Sleep]

Discussion Topics of Expectant Fathers

Discussions collected from r/PreDaddit included 1031 discussion threads consisting of 446,060 words. These discussions were contributed to by 2366 unique users across a 6-month time frame (November 2017 to April 2018). A total of 9 discussion categories were identified (see Table 2), including *Nesting*, *Pregnancy Complications*, *Budgets and Purchases*, *Standby!*, *Birth Announcements*, *Gender Announcements*, *Pregnancy Milestones*, *Fertility Issues*, and *Pregnancy Announcements*. These 9 categories were further synthesized into 3 semantic categories: *Announcements*, *Preparing for Fatherhood*, and *Pregnancy Events*, which are discussed below.

Table 2 displays the descriptive statistics of each discussion topic. Overall, the Pregnancy Complications discussion topic contained the largest number of posts, with 169 discussion threads and 1628 replies contributed by 984 users. The Birth Announcements discussion topic achieved the highest total user score, despite having only a moderate number of posts. The smallest discussion topic was Pregnancy Announcements, which contained 33 discussion threads with 111 replies, contributed by 127 users.

Table 2. Emergent categories in the discussion topics of expectant fathers in r/PreDaddit.

Topic	Discussion threads, n	Replies, n	Total user score	Word count
Announcements				
Birth announcement (users: n=432)	103	541	12,974	6088
Gender announcement (n=401)	100	459	5966	15,627
Standby! (n=343)	111	389	4321	23,913
Pregnancy announcements (n=127)	33	111	2278	2849
Preparing for fatherhood				
Nesting (n=828)	248	1227	9695	1,08,362
Budgets and purchases (n=575)	133	813	4921	81,941
Pregnancy events				
Pregnancy complications (n=984)	169	1628	12,281	1,82,278
Pregnancy milestones (n=313)	85	339	3015	18,179
Fertility issues (n=242)	49	247	4157	6823

Announcements

The first emergent category that was identified from the r/PreDaddit discussions was *Announcements*. A common type of post identified in the forum was expectant fathers sharing their excitement along the timeline of conception to birth, including the announcements for pregnancy (*Pregnancy Announcement*), gender (*Gender Announcement*), imminent birth (*Standby!*), and birth (*Birth Announcement*). Usually, the original posts were short in word count, but included highly positive language with themes of happiness and joy, for example:

> *She's getting induced tonight. Wish us luck! We're having our very first baby tonight. I can hardly contain my excitement. Wish us luck Reddit. I will report back when she's here! Update: she's still in labor, probably going to be a long one at this rate but she's doing amazing! Thank you all for your support!* [Standby!]

Replies to such posts were also extremely encouraging and congratulatory in nature, for example:

> *Congrats dude! Isn't it such a relief to finally not have to hide this major life changing news!? Enjoy the tidal wave of love and excitement from loved ones!* [Pregnancy Announcement]

After the birth of their child, expectant fathers sent their farewells to the r/PreDaddit forum as they *graduated* to the forum for current fathers, r/Daddit:

> *Graduated! Thank you so much to the kind strangers on here for all of the advice. r/Daddit, here I come.* [Birth Announcement]

Preparing for Fatherhood

Another theme that emerged from the identified categories was the preparation for fatherhood, including preparing the home for the incoming baby (*Nesting*), as well as discussions and recommendations on products and budgeting for the additional costs of having a child (*Budgets and Purchases*). *Nesting* discussions typically included expectant fathers sharing their excitement about the impending birth by showing pictures of their new nursery:

> *[Baby] will be here in 13 days or less! Here's his nursery wall I made.* [Nesting]

Nesting also included discussions preparing for changes to the family unit, including pets:

> *I don't graduate until 8th September but already trying to get things in place and was wondering how you've introduced family dogs to the new borns. We have a very boisterous red setter/lab mix and I want to get all the advice possible I can to handle the situation well. I know first off that I need to be as calm as possible about as dog will react to any feelings of apprehension but any advice welcome.* [Nesting]

The *Budgets and Purchases* topic included discussions between expectant fathers seeking suggestions on baby products, for example:

> *Now that it's becoming really real for us, I was just curious for predads that are further along and those that have graduated, what was your first purchase for the baby? When did you and your partner begin making purchases to prepare for the new family member? I'm antsy to get the car seat and nursery rocking chair figured out asap, even though those might not be the biggest priority -_-* [Budgets and Purchases]

Budgets and Purchases also included longer-term planning by expectant fathers about the upcoming costs associated with having children:

> *My wife just found out that she is pregnant (5 weeks- we were trying)! Hooray! We are very excited and know we will be "OK" with getting things ready for the baby - the only thing we're both freaking out about is childcare after birth...We both work fulltime (she works 40-80hrs/week) and both currently work weekends or sometimes her schedule is random. She*

> *will get a month or two of maternity leave. After that...? We don't have any family support anywhere near us, so I guess it is either a nanny or childcare center. Beyond the obvious freak-outs about handing off your 6-8 week year old to a stranger, we're wondering how the hell we afford something like this?* [Budgets and Purchases]

Pregnancy Events

The final emergent category from the expectant father forum was *Pregnancy Events*, which included posts about medical or miscarriage issues during pregnancy (*Pregnancy Complications*), updates about the progress of the mother and baby during the pregnancy timeline (*Pregnancy Milestones*), and posts about issues faced when conceiving a baby (*Fertility Issues*).

Pregnancy Complications included discussions on issues within the pregnancy, including miscarriages, genetic screening results, and other related issues. This category included posts about grief or shock over issues with the baby, for example:

> *No heartbeat for twins at 8 weeks. Devastated.* [Pregnancy Complications]

Despite the themes of loss and heartbreak that characterized most original posts in this category, there were also posts containing messages of support to encourage other members to keep fighting despite such setbacks, for example:

> *To all the Dads-to-be that are struggling; coming to grips with being a parent, dealing with an unreasonable hormonal partner, struggling to be loyal when not having your needs met, or even considered, struggling post-partum, remember, one day your kid will look at you and smile. Hang in there.* [Pregnancy Complications]

Another interesting theme that was uncovered in the *Pregnancy Complications* category was fathers discussing their own challenges during pregnancy, reacting to physical and emotional changes of their wife, for example:

> *I knew that she was pregnant. I knew her body was changing and that she needed special care and attention. But even though I knew there was a baby in there, I didn't really get it until the baby was born. I've talked with many of my friends who had the same experience. Months of pregnancy, birth - here is a baby! It's weird.* [Pregnancy Complications]

In comparison with *Pregnancy Complications*, the posts that were categorized as *Pregnancy Milestones* included fathers sharing updates about the progression of the pregnancy, for example:

> *After a threatened miscarriage at 8 weeks, we hit 12 weeks 6 days today. Baby steps, pun intended.* [Pregnancy Milestones]
>
> *Felt the baby kick last night.* [Pregnancy Milestones]

Interestingly, the posts in the *Fertility Issues* category involved fathers who had experienced difficulties in conceiving a baby, with many sharing news that they were now expectant fathers, for example:

> *After two miscarriages and months of fertility treatments, we are due in December.* [Fertility Issues]
>
> *Joining the club after 4 years of infertility.* [Fertility Issues]

Discussion Topics of Current Fathers

Discussions collected from r/Daddit included 949 discussion threads consisting of 319,208 words. These discussions were contributed to by 3672 unique users across a 3-month time frame (February 2018 to April 2018). A total of 9 discussion categories were identified (see Table 3), including *Struggles*, *Child's Growth and Development*, *Paternal Bonding*, *Parenting Skills*, *Feeding*, *Play*, *Dad Hobbies*, *Meet my Baby*, and *Easter*. These 9 categories were further synthesized into 3 semantic categories: *Help Seeking*, *Fathers' Practices*, and *Community Building*, which are discussed below.

Table 3. Emergent categories in the discussion topics of current fathers in r/Daddit.

Topic	Discussion threads, n	Replies, n	Total user score	Word count
Help seeking				
Struggles (users: n=2136)	277	3151	66,063	2,24,013
Fathers' practices				
Paternal bonding (n=385)	79	385	15,044	9199
Parenting skills (n=310)	70	300	7439	9430
Feeding (n=270)	69	273	4017	17,894
Children's growth and development (n=949)	238	1047	24,963	35,975
Play (n=268)	47	246	6465	7152
Dad hobbies (n=112)	31	97	2570	2413
Community building				
Reddit, meet my baby (n=758)	124	869	32,014	12,365
Easter (n=47)	14	40	675	767

Table 3 displays the descriptive statistics of each discussion topic. Overall, the Struggles discussion topic contained the largest number of posts, with 277 discussion threads and 3151 replies contributed by 2136 users. The Struggles discussion topic also achieved the highest total user score. The smallest discussion topic was Easter, which contained 14 discussion threads with 40 replies, contributed by 47 users.

Help Seeking

The first emergent theme identified within r/Daddit was *Help Seeking*. In this theme, discussions were focused on the challenges and issues fathers face in raising their child (*Struggles*), with replies consisting of other fathers providing moral support and sharing their own stories of struggling times during fatherhood. One of the primary struggles posted by fathers related to the death of their baby, evoking emotions such as sadness, heartbreak, and shock, for example:

> *Tonight, I had to make the hardest decision of my life. Hug your babies close tonight.* [Struggles]

Another common discussion point in this theme involved posts and updates by fathers whose children were battling an illness, such as leukemia or stomach problems, with those fathers reaching out to the community for moral support, for example:

> *Youngest admitted to the hospital last night. Just found out he has some kind of leukemia. His mom and I are still reeling.* [Struggles]

Apart from medical issues, fathers also discussed other issues in parenting, such as the challenges single fathers face while raising the child on their own, and day-to-day challenges such as lack of sleep because of the new baby, for example:

> *At 20, I had a kid with a girl, things happened, I got full custody, and very quickly I had to learn how to raise a child alone. Its really tough sometimes, but I wouldnt change it for the world.* [Struggles]
>
> *I thought I knew what tired was before they came.* [Struggles]

The comments left on threads in the *Struggles* category were primarily supportive, with users leaving positive messages of support to the original poster, for example:

> *Me and mine are sending our love your way. Stay strong, brother.* [Struggles]

Fathers’ Practices

Another emergent category that was identified in the r/Daddit corpus was *Fathers’ Practices*. The posts in this category included topics such as sharing bonding experiences between fathers and their children (*Paternal Bonding*), sharing questions and experiences of being a parent (*Parenting Skills*), tips and advice about feeding a new baby (*Feeding*), milestones and learning experiences with their children (*Children’s growth and development*), play time between father and son (*Play*), and fathers sharing how they like to spend their downtime while not parenting (*Dad Hobbies*).

Paternal bonding posts were primarily stories or anecdotes in which fathers described activities shared with their child, for example:

> *The Boy and I having a Batman sort of day.* [Paternal Bonding]
>
> *My 9yo son loves writing and has written several short books over the past few years. Today we took our laptops to the coffee shop to have a joint writing session. So much fun we will do it again. I may never be a great writer, but today I felt like a pretty good dad.* [Paternal Bonding]

Another major topic of discussion identified in this category was *Parenting Skills*, in which fathers would describe their progress in overcoming setbacks, learning new parenting skills, or seeking and sharing advice about parenting-specific experiences, for example:

> *Single dad with 50/50 custody. Lil guy is eight years old, so proud of him. Proud of myself over 10 months completely sober and almost two years into working on my fitness so I can be better for both of us. Life is good.* [Parenting Skills]
>
> *Anyone want to try and explain the two symbols under the umbrella (waterproof) to me?* [Parenting Skills]

Another primary theme of conversation identified in this category was *Feeding*, in which fathers would seek advice from the community about feeding their child or make humorous observations about their experiences of feeding their child, for example:

> *New dad, need help with feeding.* [Feeding]
>
> *Let’s give a happy St. Pats to all the dads drinking Guinness out of a can, washing bottles and pump parts instead of being at the pub with our mates. #adulting* [Feeding]

Fathers in this category also shared information on the growth and development of their child, including the reaching of developmental milestones, transferring of skills and interests between father and child, and other learning experiences encountered when growing up. The topics of discussion in this theme were grouped as *Children’s Growth and Development*, and posts consisted primarily of positive or humorous anecdotes, for example:

> *Little guy wanted to come to work with me today, wanted to be like dad so much he got his own uniform haha.* [Children’s Growth and Development]
>
> *She is just starting to learn to hold onto things, wouldn’t let go of this green bean in a super market. They wouldn’t let her leave without paying. Turns out 1 bean costs 4 cents!* [Children’s Growth and Development]
>
> *Congrats to the little girl losing her first tooth, here’s my youngest proudly displaying her first tooth coming in at 4 months. Relieved to find out all those fits were due to teething and not demonic possession.* [Children’s Growth and Development]

Replies from other fathers to posts in this theme were primarily positive as well, comprising humorous responses or fathers sharing similar anecdotes and stories from their own experiences.

In terms of *Play*, there were 2 main topics of discussion. First, fathers shared anecdotes and stories about experiences they had while playing with their child. In addition, some fathers also posted stories about their own *play* experiences, such as gaming, for example:

> *Howdy folks! I just recently joined your ranks and was wondering if there were any gamers out there that had any input on good games for a new dad. Basically what I'm looking for are games that are good in short bursts (not like 400 hour rpgs where you get lost if you forget where you were supposed to go), and that allow you to pause, save or quit at any time.* [Play]

Similarly, there were also several posts that were classified as *Dad Hobbies*, in which fathers described activities they enjoyed doing in their down time from parenting, for example:

> *To all the Mamas, who recognize the needs of the Daddas to go solo-watch movies about big robots fighting fish monsters & give them a nice night off of kid duties + beer money.* [Dad Hobbies]
>
> *Caught a bluefin trevally next to the USS MISSOURI with my little guy strapped to my chest!* [Dad Hobbies]

Community Building

The third emergent category that was identified in the r/Daddit corpus was titled *Community Building*. Posts in this category primarily involved fathers introducing their babies or children to the community (*Meet my Baby*). This type of post acted as an introduction and initiation into the community. For example:

> *Met my daughter at 5:04 this morning.* [Meet my Baby]
>
> *Wife and I welcomed our beautiful son and beautiful daughter into the world late last night!* [Meet my Baby]

The comments posted in response to these posts were overwhelmingly positive and congratulatory in nature, for example:

> *Congratulations and a warm welcome to this sub!* [Meet my Baby]
>
> *Congrats on your little slice of heaven!* [Meet my Baby]

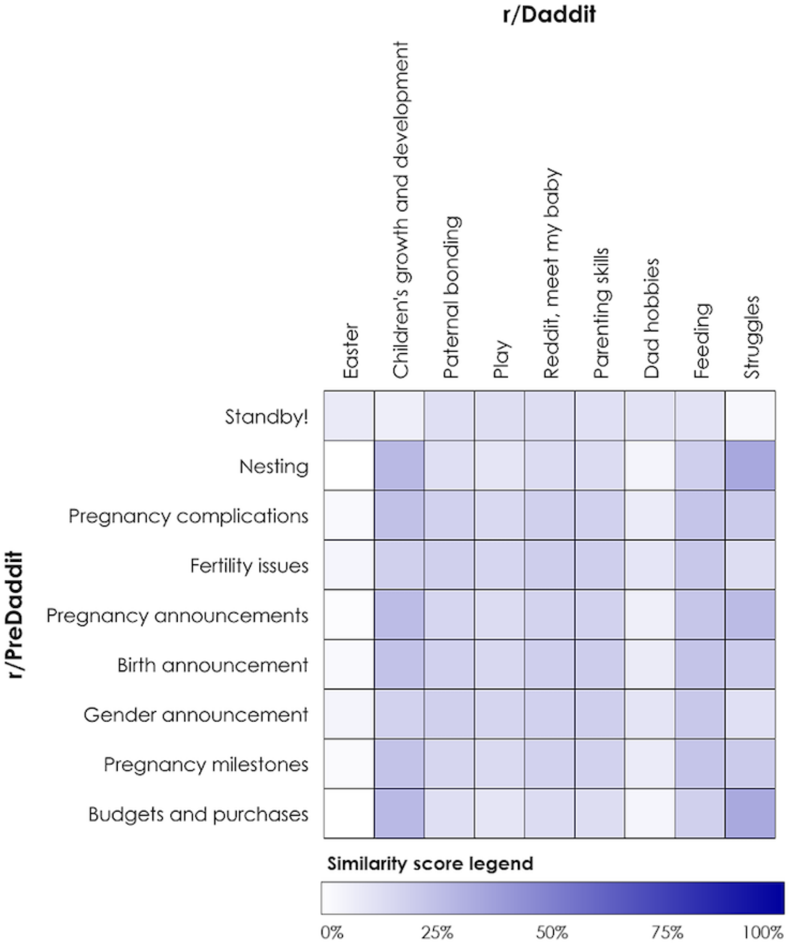
Another small theme that appeared in this category because of the time of data collection was posts about fathers and their children celebrating the *Easter* holiday, for example:

> *This has been an interesting Easter, 1 month old high fevers are not fun.* [Easter]

Comparison of Discussions Between Expectant and Current Fathers

A small proportion of users, 7.13% (403/5655), were found to post in both r/Daddit and r/PreDaddit. Overall, low Jaccard coefficients were observed between r/Daddit and r/PreDaddit discussion topics (<0.4), indicating high heterogeneity between the 2 subreddits. This demonstrates that although there is some overlap in themes discussed across r/Daddit and r/PreDaddit, these groups also contain distinct themes. The highest Jaccard score identified was between Nesting and Struggles (0.36), Budgets and Purchases and Struggles (0.36), and Nesting and Children's Growth or Development (0.30). The lowest scores were observed between Standby and Struggles (0.06) and between Nesting and Dad Hobbies (0.07), and nearly all r/PreDaddit topics compared with Easter were <0.07. Figure 1 displays the overlap between topics.

Figure 1. Overlap in discussion topics between expectant (r/PreDaddit) and current (r/Daddit) fathers, calculated using Jaccard scores.



Discussion

Principal Findings

This study aimed to assess the feasibility of using machine learning to explore the discussion topics of Web-based communities as men transition to fatherhood. This was achieved by mapping the discussion topics on 2 forums for expectant and current fathers from the social media site Reddit. In doing so, this study has demonstrated that Reddit is an ecologically valid tool for exploring current issues for men as they transition to fatherhood. Such research has important implications for the design of online social support systems for fathers and for the research methodologies used to reach and engage fathers across the perinatal period and beyond.

This study demonstrates that social media data can provide a convenient and ecologically valid method for obtaining rich information on the issues fathers face both antenatally and postnatally. As previous studies have demonstrated, the experience of fathers is often difficult to capture in formal research and support settings. Clustering the discussion topics of current and expectant fathers online revealed that fathers typically use forums such as Reddit as a platform to seek support from peers during difficult times. The discussion topics of *Pregnancy Complications* for expectant fathers and *Struggles* for current fathers were the largest discussion topics of each forum, with *Struggles* emerging as the largest discussion topic across both forums. These discussion topics also had the largest total word count and highest average word count per post, indicating that distressed fathers wrote comparatively longer posts and the online fatherhood community responded with detailed replies. These observations could suggest that social media sites such as Reddit may offer fathers some therapeutic benefits through the opportunity to write about and reflect on emotional experiences within the support network of an anonymous community. Quantitatively comparing the 2 forums indicated that distinctly different conversations occur before and after the birth of a child, suggesting that issues relevant to fathers antenatally are significantly different to postnatal issues.

Importantly, our findings reflect those observed in the wider literature exploring the transition to fatherhood, thereby supporting the validity of this novel sampling frame and analytic technique. We hypothesized that a range of discussion topics identified in the fatherhood transition literature would emerge within the Reddit fatherhood forums such as parenting practices, work-life balance issues, and spousal relationship issues. All these issues were observed within the forums but were grouped by the machine learning algorithm into broader categories. Discussions observed in our study are similar to that reported by StGeorge and Fletcher [22] in their support forum for fathers, with both *Announcements* and *Fathers' Practices* identified as 2 of the primary discussion themes in both studies. Furthermore, Ammari et al [21] identified similar discussion topics in their analysis of mothers' and fathers' discussions on Reddit, including *Cheap Products* similar to our *Budgets and Purchases* category, *Sleep Training* similar to our *Sleep* category, and *Milestones* similar to our *Children’s Growth and Development* category. These themes appear to be common to the fatherhood experience, in that there will always be advice seeking, bonding, sharing of stories, and challenges in balancing work and family life.

However, there were some differences in the discussion topics observed in this study and that reported in previous research exploring the fatherhood transition in online forums. StGeorge and Fletcher [22] identified *Isolation* as an additional discussion topic that was not observed in our analysis. StGeorge and Fletcher [22] describe *Isolation* as the experience of fathers in being neglected from infant-parent welfare. Differences in the intent and userbase of the forums analyzed in the 2 studies could have resulted in different discussion topics. Specifically, as StGeorge and Fletcher’s [22] forum was created by a health care organization to support fathers across the fatherhood transition, fathers drawn to such a group might have been prepared to discuss how health care organizations currently neglect fathers in infant-parent welfare and how such organizations can provide better support to fathers. Furthermore, perhaps the clinical setting of the forum itself could contribute to fathers’ perceptions of isolation; while Reddit integrates discussions on fatherhood into a feed of discussions on any topic of interest, the creation of stand-alone websites for discussions of a single topic could itself be an isolating method of outreach to fathers. Finally, the missing theme from this study could reflect improvements in community discourse of and expectations about involved fathers over time. The changing nature of fatherhood and improvements in the father-inclusive practice of organizations could have helped to reduce the isolation experienced by fathers over the 8 years between the Web-based discussions of participants in StGeorge and Fletcher’s [22] study and this study.

Secondary contributions from this study are the ecologically valid social support techniques that were observed within online fatherhood communities, which may have important implications for the design of support interventions for fathers both in person and online. Fathers in both forums were observed to be using social support techniques reported in other studies, such as providing encouragement, confirming that issues or experiences are common and normal, reciprocal sharing of experiences, providing advice based on experience, sharing of information and resources, and the promotion of best practice or good examples of fatherhood practices [20]. Some additional social support techniques were also observed within the Reddit community, such as the importance of humor to build social connections and the use of Reddit’s *upvote* system to provide endorsement and support to original posts and comments. Community-building techniques were also demonstrated, such as the use of *Meet my Baby!* posts to introduce new users to the group, *Graduation* posts as a farewell message by users who were leaving the group, and holiday- or event-specific discussions to share a connection between the Web-based environment and real-world community events.

Limitations

Importantly, the results of this study reflect the nature of the social media platform and community from which data were gathered. Reddit provides fathers with an anonymous platform to join a positive and supportive Web-based community of other men, with fatherhood discussions easily integrated into other discussion forums that fathers might subscribe to within the broader Reddit forum network. For researchers exploring Reddit data for fatherhood research, there are some important considerations to note. First, although Reddit is an internationally accessible website, it is likely to be biased to a Western experience of fatherhood, particularly toward North-American fathers. This is because of the site being hosted in North America, the predominant use of English across both r/Daddit and r/PreDaddit, and because of North America being the country of origin for the majority of Reddit users generally. Second, a potential limitation of Reddit is that it is difficult to determine how many passive users (commonly termed as *lurkers*) there are that may benefit from the discussions. Passive users do not actively participate in discussions via original posts or comments, making it difficult to calculate how many passive users are observing discussions and whether the discussions at hand are reflective of passive users’ experiences as well. Finally, the anonymous nature of Reddit means that the identities of users within the fatherhood forums are not verified. Although r/Daddit and r/PreDaddit are self-described as forums for current and expectant fathers, some users contributing to discussions may not actually be a father. Future research could consider comparing the discussions identified in this study with other pseudonymous or identifiable social media sites, such as Facebook or Twitter, where the identities of users can be verified and the nature of discussions are likely to differ, given the *real-world* relationships between users.

A further contribution of this study is the demonstration of applying *k*-means clustering to provide initial groupings of topics, which were further analyzed using traditional qualitative techniques. This demonstrated a new tool for researching fathers on the Web, complementing the Latent Dirichlet Allocation technique used by Ammari et al [21]. However, there are some limitations that are important to consider when using *k*-means. A common challenge in using *k*-means clustering is that it can also be difficult to identify the correct number of clusters within an unknown dataset (eg, the value of *k*), and the algorithm will produce the exact numbers of clusters denoted by *k*— even if that exact number of clusters does not exist within the dataset. In this study, we considered the results of several different values of *k* to determine which number of clusters produced the most semantically meaningful groups and then performed additional qualitative coding and analysis to uncover themes and discussion topics. Another characteristic of *k*-means is that each data point is grouped into a single cluster, whereas it is more realistic that discussion topics could comprise many subtopics. For example, in the combined groupings, we identified an entire category that was labeled *Sleep*, but we still identified some posts involving sleep in the *Struggles* category, albeit typically discussing sleep within a broader context of difficulties. Future studies could examine the effectiveness of different machine learning techniques for exploring fatherhood transitions using social media data. Finally, the size and unstructured nature of the dataset limited the opportunity for in-depth analysis of specific subtopics. Future research could consider delving further into specific topics either through text analysis techniques or through qualitative analysis using our clustered discussion themes as an initial framework.

Conclusions

This study demonstrates a novel technique for exploring fathers' experiences across the transition to parenthood by mapping the issues that men discuss with peers before and after childbirth. The discussion topics and social support techniques identified by this study can assist in the design of support programs and interventions for fathers. Importantly, using topic modeling of social media data offers unique clinical utility compared with traditional fatherhood research methods, as the discussions are current and timely and can be collected and analyzed at large scale in a short period.

Conflicts of Interest

None declared.

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Original Paper

Social Media Content About Children's Pain and Sleep: Content and Network Analysis

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Abstract

Background: Social media is often used for health communication and can facilitate fast information exchange. Despite its increasing use, little is known about child health information sharing and engagement over social media.

Objective: The primary objectives of this study are to systematically describe the content of social media posts about child pain and sleep and identify the level of research evidence in these posts. The secondary objective is to examine user engagement with information shared over social media.

Methods: Twitter, Instagram, and Facebook were searched by members of the research team over a 2-week period using a comprehensive search strategy. Codes were used to categorize the content of posts to identify the frequency of content categories shared over social media platforms. Posts were evaluated by content experts to determine the frequency of posts consistent with existing research evidence. User engagement was analyzed using Netlytic, a social network analysis program, to examine visual networks illustrating the level of user engagement.

Results: From the 2-week period, nearly 1500 pain-related and 3800 sleep-related posts were identified and analyzed. Twitter was used most often to share knowledge about child pain (639/1133, 56.40% of posts), and personal experiences for child sleep (2255/3008, 75.00% of posts). For both topics, Instagram posts shared personal experiences (53/68, 78% pain; 413/478, 86.4% sleep), Facebook group posts shared personal experiences (30/49, 61% pain; 230/345, 66.7% sleep) and Facebook pages shared knowledge (68/198, 34.3% pain; 452/1026, 44.05% sleep). Across platforms, research evidence was shared in 21.96% (318/1448) of pain- and 9.16% (445/4857) of sleep-related posts; 5.38% (61/1133) of all pain posts and 2.82% (85/3008) of all sleep posts shared information inconsistent with the evidence, while the rest were absent of evidence. User interactions were indirect, with mostly one-way, rather than reciprocal conversations.

Conclusions: Social media is commonly used to discuss child health, yet the majority of posts do not contain research evidence, and user engagement is primarily one-way. These findings represent an opportunity to expand engagement through open conversations with credible sources. Research and health care communities can benefit from incorporating specific information about evidence within social media posts to improve communication with the public and empower users to distinguish evidence-based content better. Together, these findings have identified potential gaps in social media communication that may be informative targets to guide future strategies for improving the translation of child health evidence over social media.

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KEYWORDS

child health; knowledge translation; pain; sleep; social media

Introduction

Social media provides fast, free, and widespread Web-based communication to millions of individuals [1]. For health communication, social media is used to share information, provide social support, connect health care professionals with the public, and inform research [2-6]. Social media research has explored several areas of child health, including cyberbullying [7], peer-support interventions [6,8], child health promotion, and intervention development [9,10].

Social media can quickly reach a variety of audiences with new information, providing easier access to evidence, and increasing the rate and breadth of engagement; for example, research shared over social media has been found to increase paper views, downloads, and impact factor [11-13]. Health care professionals report using social media for education and networking [14], with >25% using it to gather evidence and 15% for dissemination [15]. Communicating about health has been found to impact health perceptions, behaviors, and information seeking [16]. Up to 59% of parents report finding useful parenting information on social media [17], with up to 34% turning to social media to seek child health information [18]. In addition to their parents, 25% of adolescents report finding useful health information over social media [19]. Despite its popular use for sharing child health information, social media relies on open exchange and is at risk of sharing incorrect information [20,21]. With credibility as a barrier for accessing health-related social media [10,14], only 3% of parents report trusting child health information found there [18]. The level of engagement with social media for child health communication across multiple audiences has the potential to impact decision making and child health outcomes [2]. However, little is known about the content of Web-based information being shared, whether it is rooted in evidence, and the user engagement with that information.

Studies exploring health topics over social media have done so with varying methods and results, typically in adult populations, with studies seeming to focus on the content of and engagement with shared information, rather than exploring the level of evidence shared over social media. Studies have typically used content analysis over defined time periods ranging from 24 hours to 1 year, identifying a variety of content categories, and limited user engagement with health topics. Studies that explored health communication over Twitter reported that content primarily involved sharing research knowledge [22,23]. Over Facebook, where longer communication is more common, the content analysis in one study revealed posts focused less on sharing research knowledge and rather shared opportunities such as products, services, or health awareness [24]. Similarly, when searching Instagram, a photo-sharing platform that users have reported accessing to interact with others and share personal events [25], another study identified posts focused more on sharing opportunities through event promotion, advertisements, and health awareness [26]. A network analysis of Twitter posts identified low-level user engagement, within small conversation networks [27]. When exploring the level of shared research evidence, a study exploring Web-based blogs found that only 10% were evidence-based [28].

Despite the widespread use of social media, there remains little knowledge about what information about child health is actually being shared online, whether it is rooted in evidence, and the level of engagement with that information. As this information may influence child health decisions, it is imperative that Web-based conversations are studied. This research can help health care professionals and researchers understand what information is being sought after and shared. In addition, it can provide suggestions for overcoming barriers to accessing and using social media, and guide researchers and health care professionals to be credible sources [29-33] who positively influence these Web-based conversations, and help motivate evidence-based information seeking and sharing [34].

This study aims to take the first step in understanding and identifying the content of child health information publicly shared over social media, the level of evidence within that content, and user engagement with that information. To focus on this research, content areas were chosen to represent common child health topics that were likely to be frequently discussed across multiple audiences over social media—child pain and child sleep. Both child pain and sleep are problems that can impact multiple areas of functioning in a child’s life and have the potential to persist into adulthood [35,36]. Pain affects 1 in 5 children [37], and sleep problems affect approximately 25%-50% of children [38].

The primary goals are to conduct preliminary research to systematically collect, categorize, and describe the content of child pain and sleep social media posts and describe the level of shared research evidence across social media platforms. The secondary goal of this research is to examine user engagement with the child pain and sleep information shared over social media. Based on the existing research, we hypothesized that social media posts would cover a range of content categories with varying frequencies across platforms; the level of shared research evidence would be minimal, and Twitter would be used more often to share evidence, compared with Facebook and Instagram; and user engagement would be minimal and contained within small conversation networks.

Methods

Search Strategy

Development

Twitter, Instagram, and Facebook (groups and pages) were searched using pain and sleep as content areas. Based on the existing reviews about social media use, these social media platforms were selected for their popularity (percent of Web-based population using platforms), for being used across multiple age demographics, for being used most frequently (percentage of Web-based population using the platforms daily), and each using different modes for sharing information (eg, Twitter posts being 280 characters, Instagram posts sharing only images and hashtags, and Facebook sharing longer messages and images) [17,39-42].

The search strategy was iteratively developed and tested using keywords related to “child,” “pain,” and “sleep” with the aim to retrieve a sample size appropriate for analysis similar to previous studies [23,43-45], which was determined through pilot testing of the search strategy. The final search strategy was applied to the 3 social media platforms for a 2-week period (pain: December 2015, sleep: May 2016; see Multimedia Appendix 1 for each of the final strategies).

Netlytic, a cloud-based text and social networks analyzer, was used in the search process, as well as the analysis of social media posts. Netlytic automatically summarizes and discovers communication networks from publicly available social media posts [46]; it uses public Application Program Interfaces to collect posts from Twitter, Instagram, and Facebook (public groups and pages). Netlytic has been used in a number of studies exploring Web-based communities, including the motivation for healthy lifestyles [47], the impact of a Web-based reading program [48], and engagement of the Health Care Social Media of Canada community [49]. Owing to platform interface differences, the search strategy was adapted to each social media platform as outlined below.

Twitter

The Twitter interface permits searching simultaneously for keywords and hashtags by using Boolean operators (eg, AND, OR). Therefore, all keywords and hashtags from the final search strategy for each content area were simultaneously used to search the Twitter platform using Netlytic; this search retrieved all individual Twitter posts that included the search terms, which were subsequently screened for inclusion. Of note, individual Twitter user profiles were not searched.

Instagram

Instagram permits searches using only one hashtag at a time. Hashtags were placed before all “child” terms and individually searched using the Netlytic program. The child search results were imported into an excel document and filtered using a search option for posts that included any of the “sleep,” or “pain” terms from the final search strategy. Individual Instagram posts and corresponding comments were retrieved at this stage and were subsequently screened for inclusion. Of note, individual Instagram user profiles were not searched.

Facebook

The Facebook interface does not identify Boolean operators in the search; therefore, only 2-word searches (eg, “child pain”) were conducted at a time. Therefore, all combinations of child words (eg, child, teen, and toddler) were searched manually on the Facebook platform with each of the pain and sleep words (eg, pain, ache, and ouch). Owing to platform interface differences, Facebook cannot be searched for individual posts. Instead, the searches generated public Facebook groups and pages. Only public content was searched; therefore, individual user profiles were not explored. The lists of groups and pages generated from the search strategy were scrolled through to the bottom, until no new groups or pages were loaded by the platform. The titles of the identified groups and pages were subsequently screened according to the inclusion and exclusion criteria. Once groups and pages were identified on the basis of the inclusion criteria, all individual posts from each included group and page were retrieved using Netlytic. Each of those individual posts were subsequently screened for inclusion.

Inclusion Criteria

Public, English social media posts were included. Child pain posts describing acute, recurrent, or persisting pain were included as well. In addition, child sleep posts describing sleep (eg, sleep strategies) were included. “Child” included infants, children, and adolescents (age range 0-18 years).

Exclusion Criteria

Posts were excluded if they were non-English, ambiguous, unrelated to the population of interest, referred only to fiction, keywords only in usernames, pornographic, or linked to malware. To respect individual user privacy, and in accordance with research ethics approval, individual user profiles were not reviewed.

Selection Process

Two trained reviewers conducted an initial screen of all posts, evaluated the inclusion criteria, and removed duplicates. Posts meeting criteria were screened again, with links followed, and titles of websites and videos considered; however, entire websites or videos were not reviewed. During the screening process, social media posts were divided among 2 independent reviewers, a Clinical Psychology PhD student and a graduate-level Research Assistant, with 20% of posts screened in duplicate and discrepancies discussed. The interrater percent agreement for the pain, and sleep searches was 85% and 90%, respectively.

Data Extraction

The number of unique users for each search was collected, as well as the rates of retweets for posts collected over Twitter. Unique social media posts (identified following the removal of duplicates and retweets) were coded using a coding guide created through pilot testing that followed an emergent consensus process between 3 reviewers, a Clinical Psychology PhD student and 2 graduate-level Research Assistants. The reviewers independently reviewed random selections of 100 included posts, created content categories of the posts, met to discuss identified categories, and revised the classification scheme for each content category. This process was followed using randomly selected groups of 100 posts, until saturation and agreement of the final content categories were reached.

The final content categories included the following: knowledge; personal experiences; opportunities or products; news or events; and seeking information or support (Multimedia Appendix 2). Table 1 presents examples of included posts for the main 5 categories.

Using the final coding guide, only one content category was assigned to each post. If more than one category was present, the most salient theme was coded. If a reviewer was unsure of what category to apply to a post, they consulted with other reviewers to reach consensus. As this study aimed to explore the information shared specifically on social media platforms, the information was only extracted and evaluated from the post itself (including website or video titles), rather than the information that the post linked to. The interrater percent agreement for coding the pain and sleep content was 75%, and 81%, respectively.

Data Synthesis

Content Analysis

The frequency of each content category was summarized for each social media platform. All duplicate and retweet posts were removed from the content analysis to avoid biasing the sample.

Evidence Analysis

Social media posts were compared with the evidence available in existing knowledge syntheses (eg, clinical practice guidelines and systematic reviews) identified by literature searches and research team expertise [50-63]. A senior PhD Clinical Psychology student with experience in pain and sleep research and practice evaluated and determined whether posts clearly contained evidence; contained information conflicting with, or unsupported by evidence; contained unclear information that needed consultation; or did not contain sufficient information to assess. A second PhD student with similar expertise evaluated 20% of the posts to determine the interrater reliability calculated by percent agreement, with 91% agreement for pain, and 94% agreement for sleep. Two registered Clinical Psychologists, Dr Chambers and Dr Corkum with content expertise in child pain, and child sleep, respectively, were consulted for discrepancies or uncertainties in the evidence. Table 2 presents examples of posts consistent with research evidence. Evidence within linked material was not evaluated, only the information that was presented specifically within each social media post.

Social Network Analysis

In the context of analyzing social media communication networks, social network analysis (SNA) is often used to study how a specific topic of interest is communicated among a group of users by examining the structure of the communication network [64-66]. Relevant to this study is SNA’s ability to measure factors such as the number of two-way conversations among users (reciprocity) and compare this with the number of one-way conversations where users may distribute information but lack any further engagement with it. In addition, SNA can measure whether groups of users are clustered, indicating whether they often communicate together about the specific topic of interest in large, or grouped around multiple disconnected or loosely connected conversations (modularity) [49]. For each communication network in the study (one per social media platform), we used Netlytic to measure both reciprocity and modularity. Unlike the content and evidence analyses, all data, including retweets and duplicated posts, were included in the analysis to explore engagement with the user-generated content. Once the network structures that display interactions among users (eg, mention, retweet, or replies) were visually examined (Multimedia Appendix 3), quantitative metrics for reciprocity and modularity were used to summarize the nature of these interactions. Specifically, the value for reciprocity is the ratio of reciprocal interactions, with values closer to 1 indicating that most users are having two-way interactions. The value for modularity is the level of network clustering, with values closer to 1 suggesting that a network consists of many weakly connected users, rather than one coherent, highly connected group [67].

Table 1. Examples of social media posts for each code category for the pain and sleep searches.

Categories	Pain	Sleep
Sharing information	“New research helps children suffering from chronic pain”	“#Blog: Should You be #Cosleeping with Your #Baby?”
Sharing personal experiences	“Little kiddo recovering super well from scary hand-squooshing incident. #ouch”	“My favorite fairy tale is the one where my kid actually goes to sleep after just one story”
Sharing opportunities	“This #Nursing #job might be a great fit for you: Registered Nurse- Pediatric Pain & Palliative Care”	“Using this app will help make my kid’s bedtimes easier!”
Sharing news	“Local Art competition for school kids. 15 schools. 5000 kids. Global Year Against Joint Pain”	“Where the children sleep—stunning photos show reality of life for #refugee children fleeing”
Seeking support	“Hi, I’m 14 years old and have chronic abdominal pain. I would really like someone my age to talk to who understands what pain is like”	“Any tips for getting a toddler to stay in bed gratefully received. Tearing my hair out here”

Table 2. Examples of social media posts sharing information consistent with research evidence for the pain and sleep searches.

Pain	Sleep
"How #breastfeeding can reduce vaccination pain in children—VIDEO:[Link]"	"Study shows that children sleep better when they have a nightly bedtime routine"
"Immersive #Virtual Reality Therapy to Control Pain during Wound Dressing Changes in Pediatric & Adult Burn Patients"	"Kids often don't get the amount of sleep they need. Lack of sleep impacts learning. #Sleep"
"FDA recommends not using codeine for cough or pain in children"	"Bedtimes need to be set & kept. Kids need down-time & structured schedules—sleeping is part of healthy living for all"
"#mentalhealth issues are risk factors for #chronicpain in European teens"	"A chief reason for our pandemic of #teensleeplessness is that many kids nowadays unrepentantly sleep with their phones"

Results

Search Results

After screening and removal of duplicates, the pain search included 1133 Twitter posts by 990 users, 68 Instagram posts by 23 users, and 247 Facebook posts by 30 users from 5 groups and by 23 users from 4 pages. The sleep search resulted in substantially more posts, and a random sample was selected for analysis (20% Twitter posts, 100% Instagram posts, and 15% Facebook groups and pages). After screening and removal of duplicates, the subsample included 3008 Twitter posts by 2863 users, 478 Instagram posts by 428 users, and 1371 Facebook posts by 125 users from 31 groups and 202 users by 49 pages (Multimedia Appendix 1). The samples revealed different rates of retweets between pain- and sleep-related posts, with more retweets in the pain sample, despite a smaller overall volume of posts, with 22.15% (1133/5115) unique pain-related Twitter posts, and 71.24% (3008/4222) unique sleep-related Twitter posts after the removal of duplicates and retweets.

Content Analysis

Twitter

Pain-related posts most often shared knowledge (639/1133, 56.40% of posts). Personal experiences were coded in 32.21% (363/1133) of posts with users reporting empathy, child pain, and injury. Other categories were minimally coded, including sharing opportunities or products (68/1133, 6.18%), seeking information or support (38/1133, 3.35%), and sharing news or events (25/1133, 2.20%). Unlike the pain search, sleep-related posts most often shared personal experiences (2255/3008, 75.00% of posts), describing the impact of child sleep on parents, sleep routines, or observations of children sleeping. Other coded categories were infrequently shared, including sharing opportunities or products (362/3008, 12.03%), sharing knowledge (302/3008, 10.03%), seeking information or support (55/3008, 1.83%), and sharing news or events (34/3008, 1.13%).

Instagram

Pain- (53/68, 78%) and sleep-related (413/478, 86.4%) posts focused on personal experiences. Sleep posts of personal experiences were most often photos of children sleeping. Pain posts infrequently shared knowledge (7/68, 10%), opportunities or products (5/68, 7%), and sought information or support (3/68, 4%). Similarly, sleep posts only occasionally shared opportunities or products (55/478, 11.5%), and knowledge (9/478, 1.9%).

Facebook Groups

Most pain-related posts (43/49, 88%) were generated from one chronic pain support group. Pain posts reported personal experiences (30/49, 61%) or sought information or support (14/49, 29%), with youth often reporting that seeking support was their reason for joining. Only 4% (2/49) of posts shared opportunities or products. The 31 sleep-related groups were primarily used for parents sharing personal experiences (230/345, 66.7%), discussing children's sleep habits and management strategies. In addition, they used the groups to share opportunities or products (41/345, 11.9%), knowledge (38/345, 11.0%), and seek information or support (36/345, 10.4%).

Facebook Pages

The pain-related posts most often shared knowledge (68/198, 34.3%), provided organization updates (60/198, 30.3%), sought financial support (31/198, 15.7%), shared opportunities (26/198, 13.6%), and personal experiences (13/198, 6.6%). Similarly, the sleep-related pages distributed knowledge (mostly through websites, 452/1026, 44.05%), shared opportunities and products (318/1026, 30.99%), shared personal experiences (168/1026, 16.37%), or sought social support (85/1026, 8.28%).

Evidence Analysis

Social Media Platforms

Across all social media platforms, child pain had a higher percentage of posts consistent with evidence (318/1448, 21.96%) compared with child sleep (445/4857, 9.16%). Evidence-based pain posts were most often pharmacological pain management (105/317, 33.1%), pain characteristics (67/317, 21.1%), information about psychological (18/317, 5.7%) and physical (18/317, 5.7%) treatments, or pain assessment (8/317, 2.5%). Evidence-based sleep posts were most often educational information (180/445, 40.4%; eg, recommended sleep duration), healthy sleep practices (161/445, 36.2%; eg, not using electronics before bedtime), and behavioral strategies (78/445, 17.5%; eg, sleep training). Child pain communication had a higher percentage of posts conflicting with existing evidence (61/1133, 5.38% of all pain posts) compared with sleep (85/3008, 2.82% of all sleep posts).

Twitter

From Twitter, 20.30% of pain posts (230/1133) were consistent with evidence compared with 6.75% of sleep posts (203/3008).

Instagram

From Instagram, 16% (11/68) of pain posts were consistent with evidence compared with 0.6% (3/478) of sleep posts.

Facebook

From Facebook, 20% (10/49) of pain groups and 33.8% (67/198) of pain pages were consistent with evidence compared with 6.1% (21/345) of sleep groups and 21.25% (218/1026) of sleep pages.

Social Network Analysis

Twitter

For both pain and sleep, Twitter users engaged indirectly and did not reciprocate communication from one user to another, identified by minimal two-way, back-and-forth conversations; this was reflected by low reciprocity values (0.02 for pain, 0.00 for sleep) calculated by Netlytic's SNA. The high modularity values (0.93 for pain, 0.96 for sleep) indicated that users communicating about each of these topics interacted in small groups, clustered primarily in conversations of 2 or 3 users. Lower modularity would have indicated larger groups of users interacting together, rather than the small clusters of conversations identified in the Twitter pain and sleep networks. Similar network structures formed around Instagram and Facebook posts.

Instagram

Both pain- and sleep-related posts had infrequent two-way conversations between users (pain, sleep reciprocity: 0.00, 0.00), most often in small clusters of users (modularity: 0.72, 0.99).

Facebook

Pain-related Facebook groups and sleep-related Facebook pages did not contain sufficient interactions between users to warrant analysis. The pain-related Facebook pages and sleep-related Facebook group interactions between users were minimal (pain, sleep reciprocity: 0.02, 0.00), indicating that Facebook users do not frequently reply to, or mention others by name. Although communication was generally one-sided, modularity indicated larger groups of users having conversations than identified with the other platforms, likely because they were contained user groups that liked or followed specific Facebook pages and groups (pain, sleep modularity: 0.51, 0.53).

Discussion

Principal Findings

Content Analysis

Both child pain and sleep searches revealed that social media posts cover a range of content categories. Differences in the frequency of shared content categories emerged over Twitter, with pain-related posts primarily sharing knowledge, whereas sleep-related posts were sharing personal experiences. These results suggest possible differences in communication about the 2 child health problems over Twitter, the platform that retrieved the most posts.

The final samples revealed different rates of retweets over Twitter between pain- and sleep-related posts, with more retweets in the pain sample, despite a smaller overall volume; this finding likely reflects content differences, with sleep content being more personal (thus retweeted less), and pain content being more research-based (retweeted more).

For Instagram and Facebook, the frequencies of content categories were similar across both health conditions. Instagram was primarily used for sharing personal experiences, supporting reported motivations of using Instagram to interact with others, and share personal events [25]. Facebook groups were primarily used to share personal experiences, and Facebook pages to share knowledge. Only a small sample of pain-related Facebook groups and pages were retrieved, reflecting that additional conversations may be conducted privately (eg, closed groups) and may warrant further investigation with a more publicly shared topic. Overall, the similarities between both health conditions for Instagram and Facebook platforms are unsurprising and highlight platform interface limitations and common or expected social conduct for each platform, which may be useful to inform future knowledge-sharing initiatives.

While Instagram and Facebook groups are typically used for sharing personal experiences, they are potential sources for expanding the Web-based conversation to share more knowledge across these platforms. Continuing to increase the rate of shared knowledge, while communicating the importance of being informed, may influence the social media atmosphere about child health, helping to motivate information seeking and sharing [34].

Evidence Analysis

The highest rates of shared evidence were found on Facebook pages, contradicting the hypothesis that Twitter would share the most evidence. Facebook pages communicate to a closed audience who has chosen to follow communication. Other sources, like Twitter or Instagram, allow for wider access to public networks. Despite 56.40% (639/1133) of Twitter pain-related posts appearing to share knowledge, only 20.30% (230/1133) of all Twitter posts were consistent with the evidence, and only 6.75% (203/3008) of sleep-related Twitter posts were evidence-based. Similar findings were identified with Instagram and Facebook analysis, with pain posts sharing a higher proportion of evidence than the sleep posts. Comparatively, the level of evidence shared about child pain and sleep is not surprising, where a study of diabetes blogs found only 10% to be evidence-based [28].

These findings highlight the potential for changing how evidence is shared over social media. Many posts that appeared to share knowledge linked externally, and the linked information was not further evaluated. In future work, instruments such as the QUEST tool [68], DISCERN [69], and Health On the Net code [70] could be used to evaluate the quality of webpage information. To address the deficit of shared evidence, posts can include short descriptions of evidence within social media posts, improving the distribution of evidence by sharing it immediately, rather than requiring users to follow a link for the actual information of interest.

Social Network Analysis

Both pain and sleep networks identified limited two-way conversations, displaying low-level user engagement. Network analyses of topics on sports and politics have found networks to be large with users frequently engaging in discussion [27], illustrating the potential for expanding health communication engagement. Health care professionals, organizations, and researchers are credible sources that can overcome perceived barriers of the accuracy and validity of health information on social media [29,30]. Communicating about health has been found to impact health perceptions, behaviors, and information seeking [16]. Establishing Web-based communication as a source of credible health care information allows for two-way interactions that provide opportunities to share and distribute evidence immediately. Open dialogue can be facilitated through public Facebook groups moderated by health care professionals, Twitter chats allocated to a specific topic, or Instagram posts directed to individuals.

Many health care professionals cite perceived burden, time investment, and lack of technical skills as barriers for using social media [2,14,15]. Increasing the availability of resources illustrating risks and benefits of social media engagement and providing strategies to overcome barriers can help address the associated stigma of social networking as an engagement tool [31-33,71-73].

Limitations

This study reflected only the content of public social media posts and does not necessarily represent data shared privately (eg, closed groups and individual user profiles) across other social media sites (eg, Pinterest and YouTube) or within linked resources (eg, webpages and videos). Relative to the total number of posts on social media (>500,000 million/day), the analyzed posts on these 2 topics were only a very small portion. The retrieved posts covered a range of topics, some of which did not always fall under only one clear content area or evidence domain, potentially influencing the overall reliability of coding and classification of posts sharing evidence. Future research should consider ways to expand social media coding when one post includes multiple topics. Only 2 child health content areas were explored, child pain and sleep; future research would benefit from exploring other child health topics, such as positive health behaviors (eg, exercise), to explore communication and engagement across a wider variety of topics. Facebook groups facilitate community discussion rather than direct conversations; therefore, this type of interaction may not have been captured. Netlytic was used for data collection and SNA, which introduces limitations of functionality. For example, Instagram allows users to acknowledge posts by clicking a “like” button, a network feature that was not retrieved with this study. Finally, these data represent uncertain generalizability. Assumptions from this work can only be drawn from the 2-week data collection from unique users interacting publicly, in English, across the selected social media platforms. Although the use of the platforms addresses a wide demographic, it cannot be inferred that this is representative of all Web-based conversations about child pain or sleep.

Conclusions

This study was a preliminary step in social media research and systematically collected and described child pain and sleep communication and engagement over social media by analyzing the shared content, level of shared research evidence, and user engagement. Twitter showed the most discrepancy in information shared, with pain topics most often sharing knowledge, and sleep topics sharing personal experiences. In contrast, Instagram and Facebook groups shared personal experiences, and Facebook pages shared knowledge. These results contribute to empirical knowledge about social media information exchange and are key to inform knowledge translation activities (eg, public health campaigns targeting general public may benefit from using a person-centered, story-telling approach on platforms like Facebook, and a more news-like approach on Twitter). While many posts claimed to link to external evidence, they failed to share evidence over social media. As such, the research and health care communities would benefit from incorporating specific information about evidence directly within social media posts, to improve communication with the public, and to empower users to distinguish the evidence-based content better. The findings that the Web-based conversation about child health is primarily one-way represent an opportunity to expand engagement through open conversations with credible sources (eg, Twitter chats with health care professionals). Together, these findings have identified potential gaps in social media communication that may be informative targets to guide future strategies for improving the translation of child health evidence over social media.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Pain and Sleep Social Media Search Strategies.
[PDF File (Adobe PDF File), 119KB - pediatrics_v1i2e11193_app1.pdf]

Multimedia Appendix 2
Pain and Sleep Content Analysis Coding Guides.
[PDF File (Adobe PDF File), 49KB - pediatrics_v1i2e11193_app2.pdf]

Multimedia Appendix 3
Visual Representations of Social Networks via Social Network Analysis for Twitter, Instagram, and Facebook.
[PDF File (Adobe PDF File), 82KB - pediatrics_v1i2e11193_app3.pdf]

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Abbreviations

SNA: social network analysis

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Original Paper

Pokémon GO Within the Context of Family Health: Retrospective Study

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Abstract

Background: Pokémon GO illuminated the potential for mobile phone gaming apps to engage users and promote health. However, much work is needed to fully understand the mechanisms through which digitally supported behavior change interventions operate, particularly for children and families.

Objective: The aims of this study were (1) to explore the Pokémon GO user experience from a family perspective and (2) to investigate Pokémon GO within the context of family health.

Methods: Between January and February 2017, congruent with one of the largest anticipated Pokémon GO updates Gen 2, participants were recruited from parks, word of mouth, and social media to complete a Web-based survey. Participants were surveyed about family characteristics, interest, and experiences playing Pokémon GO and healthy lifestyle beliefs. Using a revised Godin Leisure-Time Exercise Questionnaire, a retrospective pre-post design assessed changes in parent physical activity (PA) before and after playing Pokémon GO.

Results: Self-reported data from 160 parents and 31 children were included in the final analyses (representing 129 parents and 31 parent-child dyads). Gameplay most often occurred between sons aged 10 years or younger and mothers. “Spending time together” was the most cited reason for gameplay by both parents (122/160, 76.3%) and children (24/31, 77%), followed by “it helped me go outdoors” for parents (113/160, 70.1%) and “I am a Pokémon fan” by children (21/31, 68%). Interestingly, open-ended responses indicated that gameplay could trigger both positive and negative emotional parent response. The most cited reason for app disengagement was boredom; conversely, the most cited reason for app re-engagement was in-app events. For parents, there were significant increases in minutes spent in mild (mean 23.36 [SD 66.02]; t_{97}=3.50, P<.001) and moderate (mean 21.76 [SD 53.04]; t_{130}=4.70, P<.001) PA per week after playing Pokémon GO. However, child perceptions of parental influence on PA most significantly associated with parents who reported weekly strenuous PA both before (r_s=.514, P=.003) and after (r_s=.536, P=.003) Pokémon GO uptake.

Conclusions: Pokémon GO transcended traditional understanding of digital health and uniquely reached across generations to engage users. Findings from this study highlight that, for a period of time, Pokémon GO fostered social and physical well-being for children and families through a multifaceted approach.

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KEYWORDS

family; pediatrics; mHealth; exercise; mobile health, public health

Introduction

Background

Health and behavior are interrelated. Globally, unhealthy lifestyle choices such as poor diet and physical inactivity are associated with chronic disease and reduced mortality [1]. In families, parent and child health are also interrelated through shared genetic and environmental factors [2-4]. There is strong evidence that parenting self-efficacy (belief in one's ability) and parenting behavior are key social mechanisms in the intergenerational transmission of self-regulation and consistently correlate with a wide range of parent and child physical and psychological outcomes [5-7]. Stemming from decades of empirical support and grounded in theoretical foundations [2,8,9], core behavior change strategies frequently used to promote healthy lifestyle choices in both parents and children include, but are not limited to, self-monitoring, goal setting, social support, and the promotion of self-regulation and self-efficacy [2,10-13]. Given the shift toward precision medicine and ubiquitous nature of mobile phones, there is growing interest in the utility of mobile phones to monitor, assess, and support delivery of core behavior change strategies [14-16].

Most Americans (95%) are *connected* via mobile phones and other mobile devices, and more than half (62%) of the mobile phone owners have used their phone to get health information [17]. Mobile phone and Web-based media consume a significant portion of leisure time for individuals, couples, and families [18], with increasingly more families connecting *on the go* [19]. Nearly all children below the age of 8 years live in a home with some type of mobile device and on an average spend approximately 48 min per day on mobile devices each day [20]. Due to advances in technology, our understanding of human behavior is more dynamic than static to account for the ever-changing biological, social, personal, and contextual states associated with human behavior [21]. However, much work is needed to fully understand the mechanisms through which digitally supported behavior change interventions influence behavior in everyday real-world settings [22,23]. In particular, the design of many behavior intervention technologies focuses on individual health and does not address family health in a unified manner [3]. Yet, technology and online media provide a context for people to jointly create meaningful connections [23].

Stemming from the large multimedia Pokémon franchise, Pokémon GO became a global sensation in 2016 with estimates of 32 to 65 million monthly players at the peak of its popularity [24,25]. In Pokémon GO, players search for game-related characters or animations that have been overlaid onto real-world images (ie, augmented reality) via global positioning system capabilities of a mobile device [24,26,27]. Game play that requires physical activity (PA) is also referred to as active video games and can be useful in promoting PA when played as designed [24,28,29]. Not promoted as a *health* app, there is evidence to support significant changes in PA before and after playing Pokémon GO, as well as improvements in psychological health and cognitive performance [30-40]. As such, Pokémon GO sparked several conversations, hypotheses, and theories regarding motivation to play and the potential for similar games to synergize behavior change interventions [24,41-45].

A number of Pokémon GO studies have been conducted in college-aged students and young adults [32,36,37,39,40,46,47]. Fewer studies have examined Pokémon GO gameplay in pediatric populations [26,48,49] or within the context of family health. From the limited Pokémon GO family research, it is evident that gameplay "wasn't really about the Pokémon." [26]. In both parent and child Pokémon GO players, there is empirical support for socialization and family bonding associated with gameplay [26,48]. Pokémon GO also provided families with opportunities for exercise and outdoor time [26,48]. Although parental concerns related to injury prevention were commonly reported (eg, accidents and stranger danger) [26,48], concerns were often reconciled as family gameplay was perceived to be *different* than other types of screen time, promoting exercise, cooperation, and enjoyable exploration [26,48].

Pokémon GO succeeded in providing both spontaneous and planned opportunities across settings for parents and children to use media to create, discover, and mutually engage [26]. Engagement is critical to the success of any digitally supported behavior change intervention. Engagement may be conceptualized as the intervention itself (content and delivery), the context (setting and population in which the intervention is used), and the targeted behavior [50]. Joint media engagement (JME) refers to people using media together through a variety of spontaneous and designed experiences [23]. A working assumption of JME is that what goes on between people and around media can be as important as the content designed into the media [23]. If Pokémon GO gameplay for families was motivated by factors outside of the game itself, it is valuable to explore factors and context that led to initial engagement, trends over time, and associated health benefits.

Objectives

Using family as a locus for JME and building upon previous literature, we investigated the Pokémon GO user experience from a family perspective and within the context of family health. We extended the science by exploring both parent and child perspectives of gameplay, investigated plausible theories of behavior change, and learned more about the potential for behavior change technologies that engage both the child and parent to support family health. Recommendations for future behavior change technologies aimed at promoting family health are presented.

Methods

Study Design

Descriptive survey data were collected from parents or adult caregivers "parents" who were impacted by a child or teen "child" that played Pokémon GO. The parent survey was used to understand family characteristics, parent experiences with Pokémon GO, and parent beliefs toward engaging in healthy lifestyle behaviors with their child. In addition, retrospective pre-post design was used to investigate changes in parent PA before and after playing Pokémon GO. Children and teens "children" who played Pokémon GO were also invited to participate. The child survey was used to understand child experiences with Pokémon GO as well as their perceptions of parental influence on PA. Surveys were disseminated to participants via a Qualtrics survey link. Methods and Results are described according to the Checklist for Reporting Results of Internet E-Surveys [51].

Ethics

The Ohio State University Institutional Review Board approved this study. Before participation, electronic consent was obtained from parents. Child assent and parental consent were required for participation of the child. Children could complete the survey with the assistance of a parent or research team member (semistructured interview). All participants opted to complete the consents, assents, and surveys electronically and remotely (vs in-person).

Subjects

One of the largest updates to Pokémon GO, Gen 2, was projected to release in February 2017. In an effort to coalesce recruitment and data collection with viral trends associated with Pokémon GO, an 8-week recruitment occurred between January and February 2017. Participants were recruited from the research team–initiated efforts to include word of mouth, social media announcements, and email blasts. In addition, fliers were disseminated among local parks, libraries, and coffee shops in urban (eg, Columbus, OH) and suburban neighborhoods (eg, suburban Ann Arbor, MI). Parents were included if they were 18 years old or older, spoke or read English, and had a child who played Pokémon GO. Children were included if they were 5 to 17 years old, played Pokémon GO (currently or in the past), and spoke or read English. Children were not required to have a parent in the study to participate. However, all children enrolled had a parent participate. Parents could earn US $20 and children could earn US $10 in gift cards for their participation.

Data Collection and Measurements

Participants were asked to complete a one-time data collection via a survey link. Participants were able to toggle forward and back to review or change answers. Internet protocol (IP) addresses were used to reduce the likelihood of duplicate entry from the same user. Similar to other key protected health information identifiers (eg, phone number and email address), IP addresses were removed from the dataset and not used to identify any individuals.

Parents were asked to complete 3 surveys consisting of both open- and close-ended questions:

- *Family's characteristics and Pokémon GO user experience* were obtained from a survey developed from techniques used in anthropology and human-computer interaction. The initial popularity and widespread penetration of Pokémon GO provided opportunities to observe users in the wild. The principal investigator engaged in need finding and *deep hanging out* [52-54] and created a Pokémon GO account, using the app with her child, spending time in parks and neighborhoods. To learn more about Pokémon GO itself, information was gathered from general press releases related to gameplay; visits to the Niantic Pokémon GO webpage; and trends, blogs, and feedback on social media. Iterative assessments of survey questions were discussed within a small academic Pokémon GO collaborative, which included colleagues similarly interested in exploring the Pokémon GO phenomenon for scientific value. A family snapshot was obtained from general demographic questions and questions related to family interests or goals. We inquired about the Pokémon GO user experience from the parent perspective (parent as a player), "Do you periodically check Pokémon GO throughout the day?" and parent perceptions of their child's gameplay, "Does your child play Pokémon GO on his/her own phone or parent/adult phone?"
- *Healthy lifestyle beliefs scale* [55] was used to assess parental beliefs toward their ability to engage in healthy lifestyle behaviors (eg, "I believe I can help my child to lead a healthy life." "I believe that I can reach the health goals that I set for myself."). Participants responded to each item on a Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Composite scores were averaged and presented as means, SDs, with higher scores indicative of stronger beliefs. Cronbach alphas have consistently been above .80 [56].
- A revised version of the *Godin-Shepard Leisure-Time Physical Activity Questionnaire* [57] was used to assess retrospective pre-post design and to investigate changes in parent PA since playing Pokémon GO. Days per week (0 to 7) and minutes per day (in 10-min intervals from 0 to 60+) spent in strenuous, moderate, and mild PA before and after beginning to play Pokémon GO were self-reported. A Leisure Score Index (LSI) was determined by multiplying the frequency of each level of PA by a corresponding metabolic equivalent of task value: 3 (mild), 5 (moderate), and 9 (strenuous) [27]. Individuals with LSI greater than or equal to 24 are recognized as active, whereas individuals with LSI less than or equal to 23 are classified as insufficiently active [58]. Three additional questions assessed hours of daily sedentary behavior before playing Pokémon GO [38].

Children were asked to complete 2 surveys consisting of both open- and close-ended questions:

- *Child characteristics and Pokémon GO user experience* were assessed via 19 questions consisting of demographic questions and questions related to experiences playing Pokémon GO. For example, children were asked to indicate, "Who do you typically play Pokémon GO with?" Similarly, "Did you participate in any Pokémon GO holiday events (eg, Pokémon GO Halloween?)? Please respond yes or no." An open-ended question appeared at the end of the survey, "Is there anything else you want to share with us about why you play Pokémon GO?"
- *Parental influence on physical activity scale* (14 questions; Cronbach alpha >.70) [59,60] captures parental influence on a child's PA via 4 subscales: general parenting support, active parents, past activity, and guiding support. Composite scores were averaged for a mean score, with higher scores indicative of greater support.

Analysis

Data were analyzed using descriptive analyses, including means, SDs, and frequencies. Spearman rank correlation (rho) was used to assess relationships among study variables. Qualitative data were limited, stemming from open-ended survey questions. When possible, descriptive analysis of survey comments was used to identify recurrent themes and to highlight anecdotal feedback. As missing data were minimal and to ensure study quality, only data that were 90% or more completed were included in the final analysis, yielding a 98% parent and 94% child completion rate.

Results

Family Characteristics

Self-reported data from 160 parents and 31 children were included in the final analyses (representing 129 parents and 31 parent-child dyads). Both parent (141/160, 88.1%) and child (27/31, 87%) samples were overwhelmingly white. Over 60% of household incomes earned greater than US $50,000 annually, with half of that reporting incomes greater than US $100,000, and nearly 35% of the parents had a 4-year college degree. Tables 1-3 provide the family characteristics.

Table 1. Self-reported parent characteristics (n=160).

Characteristics	n (%)
Age (years)	
18-24	14 (8.8)
25-34	65 (40.6)
35-44	58 (36.2)
>45	23 (14.4)
Gender	
Female	115 (71.9)
Male	45 (28.1)
Race or ethnicity	
Black	5 (3.1)
White	141 (88.1)
Hispanic	4 (2.5)
Asian	3 (1.9)
Native American	3 (1.9)
Other	3 (1.9)
Missing	1 (0.6)

Table 2. Parent reporting on their child’s characteristics (n=160).

Characteristics	n (%)
Age (years)	
≤10	107 (66.8)
11-15	35 (21.9)
≥16	11 (6.9)
Missing	7 (4.4)
Gender	
Female	46 (28.8)
Male	109 (68.1)
Missing	5 (3.1)
School level by grade	
Elementary (up to fifth)	123 (76.8)
Middle (sixth to eighth)	20 (12.5)
High school (ninth to twelfth)	14 (8.8)
Other	3 (1.9)

Table 3. Self-reported child characteristics (n=31).

Characteristics[a]	n (%)
Age, in years	
≤10	22 (71)
11-15	6 (19)
≥16	3 (10)
Gender	
Female	7 (23)
Male	24 (77)
School level by grade	
Elementary (up to fifth)	22 (71)
Middle (sixth to eighth)	4 (13)
High school (ninth to twelfth)	5 (16)
Race or ethnicity	
White	27 (87)
Black	1 (3)
Hispanic or Spanish	1 (3)
Asian	2 (7)

[a]Data for children consented and assented into the study.

User Experiences

For aim 1, data reflect facets of user experiences (eg, adoptability, accessibility, desirability, usability, and value) [54,61]. Before Pokémon GO, the majority of parents (142/156, 91.0%) and children (24/31, 77%) never played an augmented reality game. Parents indicated that more than half of the children borrowed a parent's phone for gameplay (82/154, 53.3%), whereas 46.7% (72/154) of children played on their own phone. The majority of parents (79/155, 51.0%) downloaded the game within a week of release, whereas the majority of children downloaded the game within a month of release (12/30, 40%). However, nearly a fifth of both parents (28/155, 18.1%) and children (6/30, 20%) downloaded the game on the day it was released. Over 40% (69/160, 43.1%) of parents never engaged with the Pokémon brand before Pokémon GO. Conversely, children identified with the Pokémon brand through television shows (28/31, 90%), card collecting (23/31, 74%), and/or books (16/31, 52%). Table 4 highlights aspects of gameplay in families.

Open-ended questions provided insight into motivation and rationale for disengagement and re-engagement with the game (Table 5). Unique to family gameplay, parenting behaviors such as screen-time monitoring or leveraging the game for child reward or punishment (eg, "child punishment was over") influenced engagement. Parent comments suggested that boredom was the main factor related to disengaging from the game, whereas in-app events brought users back to the game. These in-app events and updates could elicit enjoyment and excitement, "It is fun to see new things" and "New Pokémon!!!"

To explore gameplay within the broader context of family, parents were asked to identify 3 goals for themselves or their families. The 2 most cited goals were having fun (114/160, 71.3%) and spending more or quality time with their children (113/160, 70.6%). The third most reported goal was to exercise more (74/160, 46.3%). Making more money was the least reported goal (20/160, 12.5%). Most parents reported that playing Pokémon GO helped them to meet 2 or more of their family goals (107/155, 69.0%), and another 33% of parents reported that gameplay helped them meet 3 or more of their goals. Both parents and children cited multiple reasons for gameplay, yet "spending time with family" was the most cited reason. The majority of dyadic gameplay occurred between a child aged 10 years or younger and a parent (107/160, 66.8%). Parents reported gameplay with sons most often (111/160, 69.4%), and children reported gameplay with mothers most often 87% (27/31). Interestingly, more than half of the parents (107/160, 66.8%) reported playing Pokémon GO *for their child*, even when the child was not physically present. Table 6 provides the social perspectives of gameplay.

Profiles of Family Health

For aim 2, Pokémon GO was investigated within the context of family health. First, self-reported parental beliefs toward engaging in healthy lifestyle behaviors were relatively high. The average score was 75.00/90.00 (n=160; SD 10.2). Parental indicators of health behavior were obtained from retrospective self-reports of sedentary and PA behaviors. Sedentary behaviors were categorized into television or video watching, video game playing, or surfing the internet or Web. Watching 1 to 3 hours of television daily was the most frequently reported sedentary behavior (n=153, mean 2.71 [SD 1.93]). Surfing the internet accounted for 1 to 2 hours of daily sedentary behavior (n=150, mean 2.43 [SD 1.59]), with fewer parents reporting that they played video games (98/160, 61.3%).

Table 4. Facets of Pokémon GO gameplay.

Aspect	Parent self-report (n=160), n (%)	Parent reporting on their child's gameplay (n=160), n (%)	Child self-report (n=31), n (%)
Played game while doing something else (eg, walking somewhere and waiting in line)			
Yes	145 (90.6)	122 (76.3)	26 (84)
No	11 (6.9)	34 (21.3)	4 (13)
Missing	4 (2.5)	4 (2.5)	1 (3)
Number of times game checked throughout the day			
0	6 (3.7)	0 (0.0)	12 (39)
1	21 (13.1)	73 (45.6)	2 (6)
2 to 3	51 (31.9)	56 (35.0)	10 (32)
4+	78 (48.8)	27 (16.9)	7 (23)
Missing	4 (2.5)	4 (2.5)	—
In the past 7 days, number of episodes gameplay lasted for more than 30 min			
5+	62 (38.8)	28 (17.5)	5 (16)
3 to 4	47 (29.4)	37 (23.1)	6 (19)
2 to 3	38 (23.8)	68 (42.5)	17 (55)
0	9 (5.6)	23(14.4)	3 (10)
Missing	4 (2.5)	4 (2.5)	—
Participated in in-app events			
Yes	127 (79.4)	58 (36.3)	21 (68)
No	29 (18.1)	97 (60.6)	10 (6)
Missing	4 (2.5)	5 (3.1)	—
Participated in community-sponsored Pokémon GO events			
Yes	91 (56.9)	—	10 (32)
No	65 (40.6)	—	21 (68)
Missing	4 (2.5)	—	—
Purchased portable phone battery for gameplay			
Yes	96 (60)	—	11 (36)
No	60 (37.5)	—	20 (65)
Missing	4 (2.5)	—	—
Increased phone data plan			
Yes	28 (17.5)	—	3 (10)
No	128 (80.0)	—	28 (90)
Missing	4 (2.5)	—	—
In-app purchases			
Yes	113 (70.6)	—	—
No	45 (28.1)	—	—
Missing	2 (1.3)	—	—

Table 5. Engagement with Pokémon GO from parent perspective.

Perspective	n (%)
Stopped gameplay (permanent or temporary; n=156)	
Yes	26 (16.3)
No	130 (81.3)
Reason for disengaging from game (permanent or temporary; n=26)	
Bored or lost interest	11 (42)
Too busy	6 (23)
Addiction	2 (8)
Weather (unfavorable)	2 (8)
Completed game or level	2 (8)
Screen time monitoring	1 (4)
Game used too much phone memory	1 (4)
Technical bug	1 (4)
Reason for re-engaging with game (n=156)	
In-app events or updates	30 (57.7)
Child asked	10 (19.2)
Fun, interesting	3 (5.7)
Free time	2 (3.9)
Friends	2 (3.9)
Weather (favorable)	2 (3.9)
Change in work, social circumstance	2 (3.9)
Child punishment over	1 (1.8)

Table 6. Social perspectives of gameplay.

Aspects of gameplay	Parent (n=160), n (%)	Aspects of gameplay	Child (n=31), n (%)
Typical gameplay (check all that apply)			
With a child	97 (60.6)	With a parent	23 (74)
By myself	80 (50.0)	By myself	4 (13)
With family or friends	30 (18.8)	With family or friends	4 (13)
Played game with			
Son	111 (69.4)	Mother	27 (87)
Daughter	59 (36.9)	Sibling	19 (61)
Niece or nephew	41 (25.6)	Father	17 (55)
Grandchild	6 (3.8)	Grandparent	7 (23)
Other	19 (13.1)	Childcare provider	2 (7)
Enjoyed game because			
It helps me spend time with family	122 (76.3)	It helps me spend time with family	24 (77)
It helps me to go outdoors	113 (70.1)	It helps me to go outdoors	20 (65)
It makes regular walks interesting	111 (69.4)	It makes regular walks interesting	0 (0)
I like physical activity	90 (56.3)	I like physical activity	0 (0)
I am a Pokémon fan	48 (30.0)	I am a Pokémon fan	21 (68)
I consider myself a gamer	18 (11.3)	I consider myself a gamer	13 (42)

Table 7. Retrospective physical activity before and after playing Pokémon GO.

Physical activity type	N	Before playing Pokémon GO, mean (SD)	After playing Pokémon GO, mean (SD)	*P* value
Mild activity (min/day)	—	21.13 (11.72)	26.39 (11.38)	—
Mild activity (min/week)	98	79.59 (68.06)	102.95 (73.50)	.001
Moderate activity (min/day)	—	20.92 (14.11)	25.11 (13.03)	—
Moderate activity (min/week)	131	60.45 (62.82)	82.21 (72.91)	<.001
Strenuous activity (min/day)	—	16.57 (15.49)	18.57 (15.44)	—
Strenuous activity (min/week)	141	48.50 (60.69)	56.00 (66.17)	.03
Leisure score index[a]	160	38.25 (25.84)	48.04 (25.96)	<.001

[a] Leisure score index: frequency of each physical activity level × corresponding metabolic equivalent of task value.

Using the Godin-Shepard Leisure-Time Physical Activity Questionnaire, PA of parents was retrospectively evaluated before and after playing Pokémon GO. To account for variations in exercise routines (eg, Monday-Wednesday-Friday), weekly minutes of PA (vs daily) and an overall LSI were used for pairwise comparisons. Pairwise *t* tests compared PA levels before and after playing Pokémon GO. We applied a Bonferroni correction for the multiple comparisons of PA levels and overall LSI (mild PA, moderate PA, strenuous PA, LSI, P=.01). We found playing Pokémon GO significantly increased minutes spent in mild and moderate PA per week and overall LSI (Table 7). Although the LSI was relatively high for this sample before gameplay, LSI significantly improved from 67.5% (108/160) to 80.0% (128/160) after gameplay.

Correlations between family characteristics and health variables (parental healthy lifestyle beliefs, parental PA, and child perceptions of parental influences on PA) were assessed. Parents' education level significantly correlated with household income (r_s=.395, P=.03) and healthy lifestyle beliefs (r_s=.170, P=.03). These findings indicate that the more educated the parents, the more likely they were to have higher annual income and beliefs in their ability to engage in healthy lifestyle behaviors. However, analysis of parent-child dyadic data showed that parent healthy lifestyle belief scores (n=30, r_s=.242, P=.19) did not correlate with child perceptions of parental influences on PA (n=31, mean 30.06 [SD 5.13]). Instead, child perceptions of parental influences on PA significantly correlated with LSI, both before and after Pokémon GO (n=31, pre-LSI r_s=.503, P=.004; post-LSI r_s=.476, P=.007). Upon closer examination, the most significant association was found between child perceptions of parental influences on PA *subscale for active parents* and parent-reported minutes per week spent in *strenuous* PA (pre gameplay r_s=.389, P=.03; post gameplay r_s=.447, P=.02). Parent-reported strenuous activity also significantly correlated with child perceptions of parental influences on PA *guiding support subscale* (pre gameplay r_s=.361, P=.05; post gameplay r_s=.378, P=.04). These findings suggest that children are more likely to perceive parental influence on PA if the parent regularly engages in strenuous activity and has supportive rules for PA participation.

Discussion

Principal Findings

Pokémon GO transcended traditional understanding of digital health and uniquely reached across generations to engage users. Analogous to other research exploring interest in health apps [62,63] and Pokémon GO family research [26], our sample tended to be white, educated, and with higher than average household incomes. Although Pokémon GO sparred many conversations and lessons to be learned [24], it is critical to note that a significant portion of families are underrepresented. From our sample, it is evident that families with young children are co-users of technology. Largely consistent with previous Pokémon GO research [26,30,32-34], our findings show that for stints in time, Pokémon GO promoted physical and social well-being. Findings are presented per the following study aims: (1) to explore the Pokémon GO user experience from a family perspective and (2) to investigate Pokémon GO within the context of family health.

User Experience

Findings are presented following facets of the user experience honeycomb (ie, usability, adaptability, accessibility, desirability, and value) [54,64]. Ease of use or *usability* refers to the ease with which users can complete their intended task using a product [61]. For example, Pokémon GO was able to reach a broad audience by designing a free game for use on mobile devices (opposed to requiring users to purchase a specific gaming device). In the United States, approximately three-quarters of all Americans own a smartphone [65]. Similarly, Pokémon GO was and continues to be available across Android and iOS platforms. Yet, as a freemium game (ie, where additional features may be purchased) Pokémon GO consumed up to 50% of mobile phone–based micro transactions shortly after release [66]. We found more than 70% of parents reported in-app purchases. This was an unanticipated finding and follow-up questions regarding specific purchases were not part of the initial survey. However, our findings suggest that usability in children or family units may differ than that in individual or adult populations. We found that parents leveraged gameplay to punish or reward child behavior. For instance, parents reported, "We will use a Pokémon excursion to the zoo or a park to reward good behavior" or "Planned day outings...based on where the nest sites are.” Similarly, a child’s usability may be influenced by parental monitoring as young children are less likely to have their own mobile phone or have freedoms related to in-app purchases. In other Pokémon GO family research, parents believed that gameplay was associated with danger and threatened safety [26,48]. Thus, in families, individual gameplay particularly for young children may be linked to interpersonal relationships and influence usability.

Elements of emotional design (behavioral, reflective, and visceral) [67] that invoke emotional reaction to material objects should be considered part of the user experience [54]. *Desirability* refers to the power of a brand or image and is dependent on a user’s context [54,61]. Through collectable cards, games, books, and animated television series launched in 1996 in Japan, Pokémon remains one of the world’s most popular entities [68]. Yet, in our sample, over 40% of parents (69/160, 43.1%) never engaged with the Pokémon brand before Pokémon GO. Conversely, children identified with the Pokémon brand through television shows (28/31, 90%) and card collecting (23/31, 74%). In our sample, gameplay was most often between a child aged 10 years or younger and a parent. During middle childhood, children’s connections with their parents and family are of tremendous importance for their social and emotional well-being [69]. Although not longitudinally collected, parents’ responses to initial uptake of Pokémon GO signaled positive emotion associated with gameplay, “I love the smile my daughter gets when she catches a Pokémon,” “It is a great way to spend time with kids and their friends,” and “It is exciting to walk together and share.” Research shows that parents more directly influence learning when they choose to engage in activities with their children [23], and play, even digital play, helps families learn and connect [70,71]. Six conditions that lead to productive JME include mutual engagement; dialogic inquiry (inspire collaboration with others); cocreation (use media to build things); boundary crossing (span time and setting); intention to develop (at least one partner aims to grow through the activity); and focus on content not control (jockeying for control are kept to a minimum) [23]. In addition to these 6 conditions, Sobel et al [26] found Pokémon GO had other qualities that encouraged productive JME. Pokémon GO hinged on going outdoors, walking, and working in teams; gameplay relied on dynamic outdoor context; gameplay facilitated social connections outside of the family; and gameplay could be shared differently depending on how parents want to participate [26].

Explosive contagion *going viral* occurs when the transmission of a phenomenon becomes strong enough to overcome reluctance [72]. The spread of social phenomena mimics situations in which the willingness of individuals to adopt something new depends not only on the intrinsic value but also on whether acquaintances will adopt this product or not [72]. Findings from adult literature showed that when participants perceived strong social pressure from people around them, they were likely to play Pokémon GO while walking [35]. Individuals are embedded in social contexts; therefore, interpersonal and social processes are recognized as powerful levers for behavior change [73]. Likewise, a product is likely to be adopted if it is *accessible*. Although Pokémon GO was free to download, research has suggested that minority populations faced greater challenges playing Pokémon GO due to incentivized gameplay toward advantaged areas and away from rural places and places with larger minority populations [74,75]. Thus, ethical design must develop at an early stage and consider digital divide, equity, privacy, and autonomy [76].

Aligning product features with user needs drives a product’s *value*. Foremost, our findings reinforce previous evidence [26,34,48] that Pokémon GO provided an opportunity to support family values and fostered family bonding. The challenge of balancing work, life, and parenting responsibilities creates a uniquely stressed situation for parents [77-79]. Time, as a commodity, is extremely valuable to parents [80]. Recognizing the interaction between personal characteristics and situational factors, identity-based motivation (IBM) bridges psychological and social literature to facilitate integration with goal theories [81]. IBM assumes that identities are dynamically constructed in context and people are more likely to take action if something is identity-congruent [81,82]. The challenge of leveraging identity is that the same attribute can be motivating or demotivating within context, depending on the meaning and interpretation of difficulty [83]. Decisions and behaviors are often the result of goals and motives people possess [84]. Activating a goal can influence many aspects of behavior, including how people perceive, evaluate, and feel about the world around them [84]. The number of means attached to a given goal vary, and conversely, so may the number of goals attached to a given mean [85]. For example, in our sample, playing Pokémon GO served multiple goals through a single mean. Pokémon GO served the 3 most cited parent goals: have fun, spend more or quality time with their children, and get more exercise. Multifinality set denotes the number of goals linked to a mean, which may affect the perceived value of the mean or *bang for the buck* [85]. For a period of time, Pokémon GO was an extremely efficient use of time for families. However, goal systems are highly variable and context-dependent [85]. A different set of goals to the same mean may change in different context or circumstances [85]. Differently resourced families have different time, energy, and budget available for supporting media in a media-rich world competing for our attention [18,23]. Pokémon GO was able to re-engage nearly 60% of users who stopped the game using novelty via in-app events and updates. In our study, as context and circumstances changed over time (eg, weather and work schedules), gameplay became less *desirable* to some families. When specifically asked about re-engagement, for some, open-ended comments swayed negative, “My obsessed son,” “My kid’s bugging me about it,” and “I don’t always want to be on my phone or my son to be on my phone.” This highlights heterogeneity not only between families but also within families that can occur over time. Therefore, opposed to sustained engagement, research using digital technologies to support health should focus on effective engagement, sufficient to achieve intended outcomes [86], particularly in family interventions.

Family Health

Our findings support previous research [30,36,38], showing that when played as designed, Pokémon GO was associated with increases in PA. We found significant improvements in mild and moderate PA after Pokémon GO uptake, with the largest gains observed in mild activity (approximately 23.36 min/week). In addition, 20 participants (20/160, 12.5%) shifted from being classified as *insufficiently active* to *active* after playing Pokémon GO. We believe that part of Pokémon GO's success as a health app was the stealth health approach accomplished through gameplay. Stealth health is an intervention approach where the target is a side effect but not the primary motivator of participation (also a common gamification technique) [87]. Using this approach, behavior change occurs by shaping existing situations (eg, relaxing after dinner by watching television) into preferred situations (eg, relaxing after dinner by playing a location-based game).

Research conducted in college students show that variables from the theory of planned behavior (attitude, subjective norms, and perceived behavioral control) were significant predictors of behavioral intentions for gameplay [33,35]. Behavior change techniques (BCTs) are theoretically derived behavioral determinants identified for a given target [9]. There is empirical support favoring interventions that incorporate BCTs to increase self-efficacy and PA versus comparator [10,12,88,89]. As such, we found the following BCTs used in Pokémon GO: feedback and monitoring, reward and threat, goals and planning, shaping knowledge, and social support. The same BCTs found in Pokémon GO are also common to both gamification techniques [90-93] and pediatric health promotion apps [87,94,95]. Across BCT literature [10-12,88,89], planning is commonly used to increase self-efficacy, and self-monitoring is commonly used to increase PA. Although self-efficacy has been associated with PA behavior change [12,96], the influence of parental self-efficacy on PA evidence of a child is inconclusive [60,97]. In our study, parental beliefs toward healthy lifestyles did not correlate with child perceptions of parental support for PA. Rather, we found that parental behaviors, particularly strenuous PA, associated with child perceptions of parental support for PA. In a systematic review of mobile apps, role modeling was the only predictor of PA in children aged 6 to 13 years [95]. Other research demonstrates that perceived parental norms and role modeling are associated with healthy lifestyle behaviors in school-aged children [2,98,99], particularly influencing time spent outdoors [99].

Limitations and Future Research

Limitations of this study should be noted. The study design and convenience sample used weaken the strength of the study. We were unable to determine comparisons by child age (eg, <10 years vs ≥10 years) or gender because of limited distributions. Survey development and use of the game were conducted by 1 individual on the project; a diverse set of inputs would strengthen future research. Findings presented here reflect the lag time between academia and health relative to the pace of technology. The convenience sample data were collected 6 months after the initial release of Pokémon GO and skewed toward educated white populations. Research is needed to advance the real-world implementation of digital health interventions [22,100]. Specifically, research is needed to understand how all different types of families use media together, use competing technologies, and create equitable opportunities for JME in resource-limited families [23,101]. JME presented here is within the context of parent-child. Yet, JME is a much broader concept to include digital learning across individuals, including peer, sibling, and family. We briefly explored these relationships, discovering that 61% (19/31) of children reported playing Pokémon GO with a sibling. Finally, data were collected through self-report, and changes in PA were retrospective self-report, which may introduce recall bias and social desirability.

Conclusions

We believe this research extends the science by highlighting the Pokémon GO user experience and within the context of family health. Our findings parallel other research [102-104] suggesting that popular *pop* culture may be leveraged to promote health. However, gender (or gender neutral) associations may exist with different brands. As technology becomes more ubiquitous, equity concerns persist for reasons that transcend mere access to these tools [23,101]. Recognizing families as co-users of technology, particularly in families with children aged 5 to 10 years, digitally supported behavior change interventions that incorporate JME strategies should reflect the child's developmental stage and the dynamic nature of media use within the family. Within the ever-changing context of family life, we found a balance between the stability of family connectedness and everyday life. Our findings further suggest that Pokémon GO's success with children and families may be attributed to how gameplay became entwined with and strengthened important family values, while stealthily serving multiple other goals. In busy families, the efficiency of Pokémon GO justified gameplay. Although parents are traditionally recognized as agents of change for family health [2], findings from this study suggest that children aged 10 years or younger may serve as reciprocal agents of change by promoting engagement with digital health interventions. Pokémon GO underscored the potential for digital health, demonstrating that a single app can touch the lives of millions. With the anticipated release of Niantic's Harry Potter AR game in 2018 [105], another opportunity to broaden the science in children and families appears on the horizon.

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Conflicts of Interest

None declared.

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Abbreviations

BCT: behavior change technique
IBM: identity-based motivation
JME: joint media engagement
LSI: Leisure Score Index
PA: physical activity

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Original Paper

Mobile Device Use Among Rural, Low-Income Families and the Feasibility of an App to Encourage Preschoolers' Physical Activity: Qualitative Study

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Abstract

Background: As mobile devices are becoming ubiquitous, technology-based interventions provide a promising strategy to positively influence health behaviors of families with young children. However, questions remain about the feasibility and acceptability of intervention delivery via mobile apps in low-income, rural settings and among families with preschoolers.

Objective: The aims of this study were to understand the content and context of mobile device use for preschoolers; explore parent beliefs on this topic, including the acceptability of intervention delivery via mobile devices; and test a prototype of an app to encourage preschoolers' physical activity with both parents and children.

Methods: Parents (n=29) were recruited from 5 preschool centers in eastern, rural Colorado to complete a semistructured telephone interview regarding preschoolers' mobile device use. A second sample of parents (n=31) was recruited from the same preschool centers to view the app prototype independently and provide feedback. A third sample of preschool children (n=24) was videotaped using the app in small groups to measure engagement and record their responses to the app.

Results: Five key content areas emerged from the telephone interviews: (1) mobile devices are an important part of families' everyday routines, and parents have parameters governing their use; (2) parents often use mobile devices as a tool for behavior management; (3) parents clearly distinguish between mobile device use for learning versus entertainment; (4) parents have an overarching desire for balance in regard to their child's mobile device use; and (5) parents were generally supportive of the idea of using mobile apps for intervention delivery. From the app prototype testing with parents, participants reacted positively to the app and felt that it would be useful in a variety of situations. Testing with preschoolers showed the children were highly engaged with the app and a majority remained standing and/or actively moving through the entire length of the app.

Conclusions: Mobile devices are already integrated into most families' daily routines and appear to be an acceptable method of intervention delivery in low-income families in rural Colorado. The physical activity app represents an innovative way to reach these families and, with further improvements based on participant feedback, will provide children with a unique opportunity to practice key movement skills.

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KEYWORDS

smartphone; mobile apps; families; child, preschool; physical activity; rural population; poverty

Introduction

The use of electronic multimedia (eg, educational games, mobile apps, and personalized electronic messages) in interventions has tremendous potential to improve the health behaviors and knowledge of children and their parents, including activity behaviors. Several advantages exist in using mobile health (mHealth) modalities to deliver childhood obesity interventions, including reduced participant burden, ability to deliver more exciting and visually appealing messages, novel content formats such as mobile games, and greater flexibility [1]. To date, one of the few studies using a parent-focused mHealth intervention to target early childhood audiences reported sustained parental engagement with the smartphone app and improvement in certain diet and physical activity behaviors [2]. Among a wider age range of children, evidence suggests that electronic interventions on obesity can positively affect dietary and physical activity behaviors [3,4].

Interventions focused on early childhood are promising, in part, because early habits can translate into adolescence and even adulthood, making early childhood a crucial time to establish healthy habits [5]. Not only are children influenced by the physical and social environment of the home [6] but also parental behaviors related to physical activity have been shown to be associated with their preschool child's health behaviors [7]. Outside of preschool, young children spend a majority of their time at home, making parents and the home and family environment a strong intervention target for improving preschool children's activity behaviors.

To address these behaviors and positively influence the home environment, there is a need for novel strategies, particularly in low-resource families who may face time and access challenges to participating in educational or intervention programs [8]. With the continued rise in mobile device ownership and use across all populations, electronic formats are a realistic and desirable way to engage these families [9,10]. A recent survey by Common Sense Media found that mobile devices are nearly ubiquitous in the homes of families with young children, as 98% of children younger than 8 years live in a home with some type of mobile device, and children spend about 48 min a day using a mobile device [11]. These data are echoed by a variety of other surveys [12-15], including a previous study of lower-income families with preschoolers targeted toward rural, northeastern Colorado, which found that 91.6% (175/191) of preschoolers had access to mobile devices [16].

In addition to information on usage, parents' views about preschooler use of mobile devices have also begun to be investigated. The Common Sense Media survey reported that parents of children in the age group of 0 to 8 years have rather mixed views of children's media use. A majority of parents (76%) believe that *the less time kids spend with screen media, the better off they are*, yet 74% also believe that their *child benefits from the screen media he/she uses* [11]. With regard to specific benefits of screen media, 75% of parents of children aged between 3 and 5 years believe that media help their child with learning, and 62% believe it helps their child with creativity [11]. Other studies have reported similar tensions around parental beliefs related to mobile devices, with many parents simultaneously recognizing the potential benefits of mobile devices (such as children's learning or entertainment) and expressing concerns about potential drawbacks to mobile device use (such as exposure to inappropriate content or lack of engagement with others) [17-19]. However, beyond these overarching views of mobile devices, the specific role of mobile devices in the daily lives of families, as well as the acceptability of using mobile devices for intervention delivery in low-resource populations, remains unknown. Therefore, before moving forward with an intervention, formative research to understand the feasibility of mobile devices as a mode of intervention delivery in rural, low-resource audiences is warranted.

In addition to feasibility, it is critical to pretest intervention materials, such as prototypes of mobile device apps, to determine which concepts and materials resonate best with the target audience. The goal of pretesting messages and materials is to assess message appeal, recall and comprehension, sources of confusion or offense, and motivation to act. Siegel notes that pretesting materials will not tell researchers exactly how materials will perform, and they will identify any *red flags* in terms of unintended interpretations and executional details that need changing (colors, music, voices, timing, etc) [20]. Pretesting ensures that the final versions of materials contain messages that are clear, effective, true to the strategy, and easily understood by the intended audience and that they do not generate unintended reactions [20].

This paper presents results associated with one component of a larger, mixed-methods, formative research study designed to inform a technology-based interactive family intervention focused on young children's physical activity and eating behaviors [21]. The aims of the study component presented in this paper were to (1) understand the content and context of preschoolers' mobile device use as well as parent beliefs and values on this topic, including an exploration of the acceptability of intervention delivery via mobile devices and (2) pretest an initial prototype of an app to encourage preschoolers' physical activity with both parents and children.

Methods

Study Design

This study focused on families living in rural areas of Colorado who had a child attending Head Start or Colorado Preschool programs (ie, federally or state-supported preschool programming). For the first study aim related to mobile device use, content, and context, semistructured telephone interviews were conducted with parents of preschoolers. To address the second study aim of prototype pretesting, face-to-face interviews with parents of preschoolers were conducted to gather feedback and reactions to the prototype, which were then followed by pretesting with preschoolers. This paper sequentially presents the results associated with the (1) telephone interviews with parents; (2) prototype pretesting with parents; and (3) prototype pretesting with preschoolers. It should be noted, however, that although presented sequentially, the findings related to general mobile device use did not inform design of the physical activity app. The study was approved by Colorado State University's Institutional Review Board.

Participants

Telephone Interviews

Parents were recruited from 5 Head Start and preschool centers in eastern, rural Colorado. Parent packets, including an informed consent and phone interview interest form, were sent home in children's backpacks in the spring of 2016. Parents had 2 to 3 weeks to return the interest form; preschool center staff were engaged in the process to encourage families to participate. In total, 110 participants returned a form, expressing interest in the phone interview. To ensure representation across sites and demographic groups, participants were stratified by site, parental education level, and ethnicity. A total of 73 participants were then systematically chosen to contact from within these groups, and 29 completed the phone interview. All those completing the phone interview received US $20.

Prototype Pretesting

Parents

In the spring of 2017, parent packets were sent home in children's backpacks at the same 5 Head Start and preschool centers to recruit additional parents to gather reactions on a prototype of an app to encourage physical activity among preschoolers. Parents again had 2 to 3 weeks to return the interest form; a total of 102 participants returned the form. Participants were stratified by site and child gender; 60 were systematically chosen from these groups to contact, and 32 completed the interview and were compensated US $40 for their time.

Preschoolers

Preschoolers were recruited from a university-affiliated preschool that serves families from a full range of income levels. To engage preschoolers to test the app prototype, an informational sheet was distributed to parents, who were given 2 weeks to opt out of participation for their child. Only 1 family opted out of participation. All other children at the preschool who were between the ages of 3 and 5 years and were present on at least one of the pretesting days participated (n=24).

Study Procedures

Telephone Interviews

Semistructured telephone interviews were conducted with parents to understand the role of mobile devices in their families' daily life. The semistructured interview schedule consisted of 25 questions with probes and was designed to produce comparable, descriptive information about model device use [22]. Key topics included child mobile device use, typical household practices related to mobile device use, and parent values and beliefs related to mobile device use. At the end of the semistructured telephone interview with parents, participants were also asked for their opinions regarding the feasibility of hypothetical intervention components, including an app to encourage physical activity. Sample questions are presented in Table 1.

Experts in child development, public health, technology and instructional design, medical anthropology, and pediatrics reviewed the interview script, and it was piloted with 2 members of the target audience to finalize the order, flow, and wording of questions. The interviews were conducted by 2 research associates, who had each been trained in qualitative research and interview best practices [23]. Interviews ranged between 20 and 35 min, and all were audio-recorded with participants' permission. Preliminary analysis of the telephone interviews included member checking, in which key points and interpretations from each interview were summarized and sent to the interview participants for feedback.

Prototype Pretesting

Parents

As part of a longer interview with parents about their preschooler's physical activity (data reported elsewhere), a 5-min prototype of a mobile app to encourage physical activity in preschoolers, *Jungle Gym*, was shown to parents to gather their feedback. Parents viewed the app without their children and were asked to anticipate how it could be used. They were also asked their general thoughts about the app, what situations they could envision their preschooler using the app, and how they would use the app with their child.

The app is intended to enhance language related to movement, help children practice gross motor skills, and provide an opportunity for parents and children to interact together related to movement if they so desire. Although mobile devices are often perceived as sedentary devices, the development team sought to create an app that would facilitate movement in young children and model the kinds of off-device play activities that would also make children more active. The app begins when an animated character invites the user to go on a jungle adventure and states, "we will be moving our bodies, so make sure you have plenty of space." After this introduction, the child can set the iPad on a surface and go through a series of short adventures, each highlighting a specific motor skill: running, jumping, leaping, hopping, galloping, or side-stepping. For example, users are asked to run quickly through the jungle to escape rain, jump to harvest a mango from a tree, or hop alongside a frog (Figure 1). The short adventures or *scenes* are presented to the children in a random order each time the app is played in an effort to sustain children's interest in engaging with the app.

Table 1. Sample questions asked in semistructured telephone interviews with parents about mobile device use, context, and content.

Overarching question	Probes
If you think about the last day or so, when did your child use a smartphone or tablet throughout the day?	Where do they use the mobile device? (inside the home, outside the home); Was this a typical day?; How did this use compare to a weekend day?
What are the main factors influencing when or how long your child uses a smartphone or tablet?	Does it depend on any of the following: who is supervising them, family schedule, weather?
What are some benefits of your child using a smartphone or tablet?	What are the benefits to you?; What are the benefits to your child?
Some parents have rules about how their child can use a smartphone or tablet. Other families do not. Do you or your family have any rules about how your child can use the smartphone or tablet?	If so, how or why did you come up with this rule?; If so, how well do these rules work?
Please tell me if there are any times or reasons that you encourage your child to use a smartphone or tablet?	Are there any specific places, situations, or times during the day that you encourage them to use a mobile device?; How easy or hard is it to encourage your child to use a mobile device?
Please tell me if there are any times or reasons that you discourage your child to use a smartphone or tablet?	Are there any specific places, situations, or times during the day that you discourage them to use a mobile device?; How easy or hard is it to discourage your child to use a mobile device?

Figure 1. Screenshots of mobile app prototype to encourage physical activity among preschoolers.

Preschoolers

The app prototype described above was further refined based on parental feedback and was then tested with 24 preschoolers to understand children’s initial reactions to the app. Children were taken out of their classroom in groups of 3 to the gym room of the preschool by 2 members of the research team. The app was introduced to the children, including a brief explanation that they would be asked to stand up and move along with the characters in the app. The 4-min app prototype was shown to each group of children 1 or 2 times (children were allowed to go through the app a second time if they asked to do so). After using the app, children were asked if they enjoyed playing the app, as well as what they liked and did not like about the app. In total, the activity lasted about 10 to 15 min per group, and children’s use of the apps and reactions were recorded via videotape and researcher notes. In this session, children used the app in small groups, without their parents.

Data Analysis

Telephone Interviews

After sending summaries to participants for member checking, no additional information was provided. Using best practices for reproducibility in qualitative data preparation [24], all interviews were deidentified and transcribed verbatim by a Health Insurance Portability and Accountability Act–compliant vendor, verified for accuracy, and the verified transcripts imported into NVivo qualitative data analysis software (QSR International Pty Ltd Version 11, 2015). Two team members read the interview transcripts several times, and each created a preliminary codebook, including codes and definitions organized by overarching category. Three trained research team members coded 2 interview transcripts together to further refine code definitions and inclusion and exclusion criteria. Next, the 3 coders independently completed 1 set of coding with 3 transcripts, followed by a second set of 3 transcripts and established high interrater reliability (kappa=0.90 and 0.94, respectively). The remaining transcripts were split between 2 coders, with each reviewing the initial coding of another. Discrepancies were resolved through discussions with the third coder. Summary reports were generated by code, and thematic analysis was used to analyze the results [25]. Two researchers independently read through all the quotes associated with each code, and each identified emerging themes. The researchers met several times to achieve consensus and further refined each theme in the context of both the original codes and entire dataset.

Prototype Pretesting

Parents

Parent’s reactions to the app prototype were also recorded and transcribed verbatim. A general inductive approach was used [26], in which the responses were analyzed by 2 researchers who independently read transcripts multiple times, discussed the responses to reach consensus, and generated a summary of participant responses.

Preschoolers

The research team reviewed the notes and videotapes of the children using the app to understand whether the app represented a feasible approach to engage children. General reactions and engagement level, such as asking to play the app again and statements of what kids liked and did not like about the app, were compiled. Two researchers watched the videos multiple times to provide a general estimate of the percentage of time each child spent engaged in the following 4 categories: moving along with the characters as directed, engaging in other active and creative movements, becoming distracted by something else in the gym room, or no movement (sitting down).

Results

Participant Characteristics

In the telephone interviews addressing mobile device use, content, and context, 93% (27/29) of the participants (n=29) were mothers, 41% (12/29) identified as Hispanic, and 66% (19/29) represented households making less than US $49,999 per year. Phone interview participants represented a wide range of education levels, with 45% (13/29) of participants having a high school diploma or less. In the prototype pretesting phase with parents (n=31), 77% (24/31) of participants were mothers, 36% (11/31) identified as Hispanic, 62% (19/31) represented households making less than US $44,955 per year, and 33% (10/31) of participants had a high school diploma or less. Only1 participant completed both interviews. The preschoolers who tested the physical activity app were aged 3 years (n=1) and 4 years (n=23), and 50% (12/24) were male.

Telephone Interviews

Five key themes emerged from the telephone interviews: (1) mobile devices are an important part of families’ everyday *routines*, and parents have parameters governing their use; (2) parents often use mobile devices as a tool for *behavior management*; (3) parents clearly distinguish between mobile device use for *learning versus entertainment*; (4) parents have an overarching desire for *balance* with regard to their child’s mobile device use; and (5) parents were generally *supportive* of the idea of using mobile apps for intervention delivery.

Routines and Family Guidelines

Mobile devices have become a part of family routines, as a majority of parents indicated that their child used a smartphone and/or tablet daily or almost daily. All families owned at least one mobile device, and nearly half of children had their own device. Children used mobile devices for both learning and entertainment purposes, such as watching videos (YouTube for kids was particularly popular) or playing games based on cartoons and other characters popularized through television. Families varied in when the child used mobile devices, and many had strong feelings as to when the child could or could not engage with the device (ie, in the morning before school or before bedtime or while parents needed the child to be occupied).

Some parents co-used mobile devices with children most commonly to show a child how to use an app for the first time, to take turns playing a game, or to help them learn something. Many parents valued it as time spent together, particularly when it meant *cuddling up* or *sitting really close together*. However, other families mentioned that they played together in other ways and viewed time with mobile devices as an alone activity or *alone time*.

Parents had a variety of parameters in place to manage their child’s use of mobile devices, particularly related to content and timing of use. To control the content that their preschooler accessed, parents used parental locks or child modes, monitored which apps their children used, had specific *kid areas* on devices, or simply engaged in conversations with the child to convey what children were allowed to use. No matter the strategy used, the primary concern of most parents was that their preschooler would see something *inappropriate*, followed by a concern that something would *get messed up* on the device.

Other important guidelines were related to the overall time children spent using devices. Whether an enforced rule or a more theoretical ideology, many parents mentioned that children were allowed to use devices only for a certain amount of time each day, particularly in the home setting. These time limits were usually set because parents did not want children to be *glued to a screen* all day and wanted them to get a variety of experiences in childhood, ranging from playing outside and getting dirty, developing social skills through interaction with other children and adults, and using their imagination:

> *I do try limiting it as much as I can. I’d rather them be outside playing and being kids.*

Most participants had family-specific guidelines in place related to the situations in which their child was allowed to use the device. For example, policies on use before bedtime was mixed, as some families did not allow device use close to bedtime, whereas other families encouraged it at this time to help the child unwind. However, there was a consensus among parents that children should not use mobile devices during mealtime:

> *At dinnertime, we have no iPads or tablets on the table. You know that’s family time.*

A large number of parents also did not allow preschoolers to use devices while spending time with extended family and/or friends, as parents preferred them to be socializing and interacting:

> *When we’re with family we try and have him not just be buried in his tablet and be part of the whole family together.*

Behavior Management

Parents also commonly used mobile devices for behavior management. Nearly every parent felt that mobile devices were helpful to occupy children so that the parent had time to get something done, such as an important phone call, finishing work, household chores, or fixing dinner:

> *Oh, well, play this game here quietly so I can get this done.*

Many parents also used mobile devices to keep their children entertained and quiet outside the home. Parents frequently mentioned that their child used mobile devices on long car rides when the family had an unexpectedly long wait in line, doctor's appointments, or restaurants. There was a particular focus on using mobile devices to prevent preschoolers from *screaming* or *running around and going crazy* in these kinds of public settings:

> *It's really nice to have to keep him entertained and keeps him from melting down in the restaurant, or in the doctor's office or somewhere.*

Some parents did express guilt at using devices in this way, but almost all seemed to have accepted it as a useful, and occasionally necessary, way to manage public outings. One mother summed it up well:

> *I was always that parent before who was like, "No. My kid will never play on electronic devices." Then you take a five-year-old out in public, and then they throw a fit, and you're just like, "Here. Take it."*

Beyond serving as an entertainment tool in public or when a parent is occupied, mobile devices were used strategically (eg, as rewards and consequences):

> *It gives me leverage with him. It's his currency.*

This quote reflects the sentiment of many parents: mobile devices are an effective tool parents use to manage behavior. Smartphone or tablet time could be taken away for refusing to share with a sibling, doing something inappropriate on the device, or even for poor behavior unrelated to mobile devices, such as *throwing a fit*, acting up, or not listening. On the other end of the spectrum, extra smartphone or tablet time was frequently offered as a reward for positive behavior, and many children had to earn their time on mobile devices by doing chores, such as picking up their clothes or toys. It is worth noting that a small group of families did not see mobile devices as a reward or consequence for their children. These families fall into 2 categories: those whose children do not use mobile devices frequently enough for it to be an effective reward and those families whose children exclusively use devices for learning, and thus taking it away would not be considered an appropriate strategy.

Learning Versus Entertainment

A clear difference in parent beliefs and practices emerged between children's mobile device use for entertainment and learning. Nearly every parent mentioned that they wanted their child to learn from mobile devices. This learning fell into 3 main categories: learning how to use technology, in general, to be prepared for a technology-driven world; learning school readiness skills such as numbers, shapes and letters; or learning about a specific topic area that was of special interest to their child:

> *Of course technology is taking over the world, so it's good that she is getting to learn how to use a tablet.*
>
> *It's beneficial in some learning areas...I want him to basically be prepared for kindergarten.*

The last category of learning may be especially relevant for rural communities, as some parents mentioned technology as a way for children to understand more about the broader world outside their small town:

> *...just to gain background knowledge. We live in such a small town, we don't necessarily get to see everything that maybe we would elsewhere.*

Although a majority of parents mentioned learning as a benefit of mobile device use and wanted their children to be learning from devices, they also depended on the devices for entertainment in the behavior management situations mentioned above. Similarly, despite parents' desires and values for children to use mobile devices for learning, most children used the devices for entertainment, both inside and outside the home. It should be noted, however, that children used different kinds of devices based on the activity: children were more likely to use smartphones for entertainment, whereas they used education-specific tablets (such as an Innotab, Nabi) for learning purposes. Furthermore, parents were more likely to co-use devices with their children when the use involved learning. Finally, parents tended to feel better about their children's overall mobile device use when the child was learning from it, and many parents actually encouraged further use when educational content was being accessed:

> *I don't think being on the phones or the tablets is a bad thing if they're learning while they are on there.*

Similarly, parents tended to be less strict with time limits when children were using educational content versus entertainment in the home:

> *I'm a little more lenient when he's playing an educational game.*

On the other hand, when devices were used for entertainment outside the home for behavior management, for example, waiting for appointments or at restaurants, many of the *rules* related to time limits did not seem to apply. Thus, mobile devices serve distinct purposes that are situationally dependent for children.

Balance

Overall, mobile device use is all about balance in these families. It is a balance between ensuring that children are learning while also keeping them entertained when the parent needs to get something done or the family has a long wait in a public setting. It is a balance between children understanding how to use mobile devices in a technology-driven world and children developing important social skills through off-screen interactions with friends and relatives. A quote from 1 mother clearly sums up these sentiments:

> *I really just didn't want my children having their entire lives ruled by technology, but I didn't want them to be so far out of the spectrum that they are typing with two fingers…enough to get them the*

> *knowledge base that they need without taking away the time that they spend with their friends and their family and outside.*

Mobile Apps for Intervention Delivery

A majority of parents responded positively to the idea of using mobile apps, particularly if they were approved by the preschool center and helped their child to learn in some way. Most parents expressed that any mobile apps encouraged as part of a program through their preschool would simply replace existing mobile device activities, so the overall amount of time children spent on devices would not necessarily increase. In response to the idea of an app to encourage physical activity, parents were supportive, particularly if the app would help their preschooler to be active while using a device. A few parents did express doubts about the idea, as they felt that being active required putting down all devices and going outside to play:

> *You can't learn how to ride a bike from a phone.*

However, a majority of parents reacted positively to the idea, saying that it would be "cool," "fun," and "[their child] would love that." Many parents felt that the app was something their child would actually use. Several mentioned the app would be especially helpful during the winter or other inclement weather to give children a structured way to get up and move around indoors:

> *I think that would be good for maybe wicked cold, snowy days or really rainy, funky days. It still gets them up and moving.*

Prototype Pretesting

Parents

Following the initial feedback, a prototype of the physical activity app was developed, and prototype pretesting was completed with parents to understand their reactions to an actual app prototype. Parents reacted positively to the app overall and thought it was a helpful way to combine mobile device use and activity. Parents were split on whether or not they would use the app with their child. Some parents felt that the app would be a good opportunity to engage with their child related to activity:

> *It might be something that I would try to use to do exercising and stuff together with him.*

However, others expressed that they would use the app for behavior management, stating it would be helpful to *bring them down a little bit, while still keeping them active* or to entertain the child while the parent was getting chores done:

> *That would be a good one she can do while I'm doing laundry or something like that.*

A few parents expressed concern about whether or not the app would be sufficiently engaging for their child. Several confirmed the opinions of previous parents that the app would be useful for encouraging child activity in the winter or on cold rainy days when it was not possible to be active outside. Other parents had even more creative ideas for using the app, ranging from lines at the grocery store to pit stops on road trips:

> *Anytime that there's not enough space to do the full running activities, things like that. Car trips, probably, pit stops along road trips. It would be handy.*

Preschoolers

Overall, the pretesting with preschoolers demonstrated that they were engaged by the app, and all children completed some physical activity as instructed by the app. When asked what they liked about the app, responses ranged from *the animals* to *it was fun*. When asked what they did not like about the app, a few children said it made them *tired*, indicating that they were putting a full effort into their movement. As they all asked to play more than once, all groups (n=9) of children used the app 2 consecutive times, and several groups expressed disappointment when they were not allowed to go through the adventure a third time. In 8 of 9 groupings, children remained standing and/or moving throughout the entire length of the app. In 6 groups, children were very active and were continuously engaged in either app-directed movements or were inspired to do other creative movement activities (running in circles, acting out animals, etc). Overall, there did not appear to be any difference in the level of engagement between the first and second round of use. Children's reactions or confusion on specific interface issues were also recorded. A few of the children misunderstood directions related to more complicated motor skills, and it was observed that some children tended to move only when the character was talking, so the research team recommended that the voiceover script should be updated to increase clarity on directions for certain motor skills and increase repetitions to keep children on task and engaged as much as possible with each activity. Additionally, a moving figure will be added to the app to demonstrate all movement skills. Additional recommendations made to the developers included improvements to the storyline, including more animals to meet on the jungle adventure and silly noises. These recommendations will be incorporated in future versions of the app.

Discussion

Principal Findings

The overarching goals of this study were to understand mobile device use in the target audience and pretest a prototype of an app to promote physical activity among preschoolers as 1 piece of a larger formative research study designed to inform a technology-based interactive family nutrition and physical activity intervention. The first component of this study deepened the understanding of preschoolers' use of mobile devices, the role that mobile devices play in the daily lives of lower-income rural Colorado families and demonstrated the acceptability of intervention delivery via a mobile platform. The second component confirmed the feasibility of the app and gathered crucial feedback from parents and children, which will be used to inform improvements in the app moving forward.

Telephone Interviews

Mobile devices are an important part of everyday routines in these families, echoing other findings that preschoolers are frequent users of mobile devices [12-15]. In contrast to the

Common Sense Media Survey 2013, which found disparities in tablet ownership by family income level [12], every family interviewed had multiple mobile devices, and about half of preschoolers actually had their own mobile device. However, there was some evidence of the disparities in access to educational content among lower-income families, as identified by Common Sense Media 2013 [12]. Many parents in our sample mentioned that they were not able to afford any sort of paid educational content, which could potentially be associated with limits on the quality of educational materials that low-income children are accessing.

Beyond the incorporation of mobile devices into family routines, another clear content area that emerged was the use of mobile devices for behavior management, reflecting findings from several other studies [17,18,27,28]. Even before the onset of mobile devices, Rideout et al found that parents commonly used media *to keep their kids occupied while they [parents] get chores done* [17]. In 2010, Chiong and Shuler observed the *pass-back* effect in which parents would deliberately hand over their own smartphone or tablet to their young child to keep them occupied and entertained in a public setting [27]. More recently, 2 other qualitative studies, encompassing families from a variety of locations and socioeconomic backgrounds, also found that parents used mobile devices to keep children quiet or entertained when the parent needed undisrupted time to get something done [18,28].

A final content area was the clear distinction between the use of devices for learning versus entertainment and the desire for balance in children's mobile device use. In the home, parents strongly preferred educational content and would even relax the rules about time limits or encourage additional use when they felt their child was learning. However, if the child was watching a video or playing a noneducational game at home, time limits were more strictly enforced, and children were encouraged to do other activities. Outside the home, when parents were using mobile devices as a tool for behavior management, they simply wanted to keep their child entertained and did not have a strong preference as to the content that they were accessing. Thus, parental values and beliefs may be conditional, whether they are conscious of it or not.

Other studies have found a similar desire for balance related to mobile device use in families with young children [17-19]. For example, Radesky et al also found that parents expressed tension between the potential educational benefits of mobile devices and the potential negative effects on social skill development [18]. These parents similarly struggled with the usefulness of devices in keeping children entertained and quiet versus missing quality family time [18]. Another report on media use with young children found that parents appreciated that media allowed for *me* time and the ability to get things done and also exposed their child to a variety of new learning experiences [17]. |Finally, a survey of parents of children 6 months to 5 years of age found that the top 3 parental motivations for child media use were the child's enjoyment of the media, the educational value of media, and media use so that parents can accomplish their own chores, again indicating the importance of balance in mobile device use [19].

Prototype Pretesting

Additionally, this study demonstrated the feasibility of a mobile app to encourage physical activity among preschoolers. In general, parents were supportive of the concept as well as the initial app prototype. Although the app will likely not serve to keep children calm and quiet in a public setting, parents envisioned a variety of scenarios in which the app would be useful, ranging from breaks on long car trips to snowy days where children were stuck inside and needed an easy way to be active. A few parents expressed concern that the app would not be entertaining enough for some children, but children were engaged by it and wanted to play it several times. This may address the need to help communicate the appeal and value of the app to parents so that they choose to offer it to their children. Prototype pretesting with preschoolers indicated that the approach to the app is feasible, as children reacted positively to the app. A majority of children were up on their feet for the full length of the app, indicating that the app has the possibility to encourage activity in this age group. Furthermore, children were actively moving in a similar way during the first and second rounds of use, indicating that app has the potential to sustain children's interest through multiple uses.

Implications for Research and Practice

The physical activity app that was pretested as the second part of this study represents an innovative way to tap into parents' desire for balance in mobile device use. It fulfills parents' desire for there to be a learning benefit for children, as they will not only be learning language related to movement but will also be practicing foundational gross motor skills. The app appears to have utility for children for both independent and co-use settings, indicating it can be easily used by families in which children primarily use apps alone and in families where co-use is more frequent. In prototype pretesting, preschoolers were entertained by the app, which would give parents a few minutes of time to get other tasks completed while providing a healthy alternative to sedentary apps. At the same time, some parents mentioned that they would engage with their children around the app. Additionally, if presented in the right way, the app could serve as inspiration and a way to launch additional parent-child interactions related to movement in real-world settings.

Strengths and Limitations

A key strength of this study was the focus on low-income, rural families, as there is limited literature on the use of mobile devices with preschoolers in this population. Second, the telephone interview script had multiple probes and gave participants ample time to share their full values and opinions related to mobile device use in their families. A rigorous data analysis was performed, as exemplified by the phone interview transcripts being comprehensively coded in multiple rounds and then further analyzed for interpretation. Finally, prototype pretesting was conducted with both parents and children, getting valuable initial input from both groups of targeted users.

However, this study is not without limitations. Although every effort was made to encourage participation from all families enrolled at study preschools, a selection bias may have occurred as recruitment flyers indicated that the interview topic would be mobile devices. Therefore, parents who were frequent users of mobile devices may have been more likely to participate. Due to logistical constraints, the preschoolers who tested the app were a sample from a local preschool, rather than a rural preschool. It is unlikely that these preschoolers are substantially different from their rural peers in response to mobile apps, but future rounds of testing will be conducted in a rural setting with children of lower socioeconomic status to confirm this assumption. Future steps will include testing the app with parent-child dyads to assess parent-child interactions related to the app as well as exploration of individual intervention components, such as the app, on health outcomes (ie, physical activity).

Conclusions

As mobile devices are already integrated into most families' daily routines, a free app for study participants could serve as an innovative mode of intervention delivery. Most families in the settings that were sampled already allowed their children to play on devices every day. In the interviews, parents indicated that if they were provided with this type of educational app, it would be used as a replacement for existing activities on mobile devices, easing concerns that an intervention delivered through mobile devices would dramatically increase young children's screen time. Although this study focused on pretesting of a physical activity app, the findings related to parents' beliefs, values, and practices related to mobile device use, which can be applied to other health and nutrition subject areas. Thorough formative research, combined with mobile app development and prototype testing, ensures that mHealth intervention strategies are accepted by and fit into the daily lives of preschoolers and their families living in rural communities.

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Conflicts of Interest

None declared.

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Abbreviations

mHealth: mobile health

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Original Paper

The Impact of Exercise Intensity Feedback Using Technology for Children During Active Play: Pilot Study

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Abstract

Background: Most children do not engage in enough exercise at the recommended intensity. Using technological devices may increase the time children spend at greater intensities while exercising.

Objective: This study aimed to determine if children who are receiving instant feedback on their exercise intensity using technology would spend more time in moderate-vigorous intensity (≥70% of maximum capacity) during active play sessions. It also aimed to explore if the children’s physical characteristics were associated with the average percentage of maximal heart rate (HR) reached during sessions.

Methods: Participants were asked to wear a HR monitor, attached around their chest, for 4 sessions out of the 15 sessions offered. Twenty children aged 5 to 11 years received feedback for 2 random sessions. When receiving feedback, color-coded intensity based on HR was projected onto a wall. Green corresponded to moderate intensity (≥70% of max HR) and red corresponded to a HR below moderate intensity. Age, anthropometric measures, muscle strength, body composition, physical activity level, and fitness level were measured.

Results: The average percentage of maximal HR during a session was similar whether feedback was provided (70.7%, SD 6.4%) or not (71.1%, SD 4.1%) with P=.93. No personal characteristics were associated with the average intensity recorded during the exercise sessions.

Conclusions: Receiving instant exercise intensity feedback is not associated with a higher proportion of time spent at moderate intensity or above in children aged 5 to 11 years when involved in an active play program. Personal characteristics are not associated with the intensity recorded when participating in an active play program.

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KEYWORDS

biofeedback, exercise intensity, physical activity

Introduction

Moderate intensity exercise is often defined based on a percentage of estimated maximum heart rate (HR), estimated by subtracting a person’s age in years from 220, ranging from 50% to 70% [1]. Polar Canada [2] characterizes moderate-vigorous intensity as 70% or higher of an individual’s maximum HR. Physical activity performed at moderate-to-vigorous intensity is associated with a lower risk of (1) obesity, (2) elevated cholesterol levels, (3) hypertension, and (4) metabolic syndrome in children [3]. A small proportion of Canadian children meet the World Health Organization physical activity guidelines which recommend 60 minutes per day of moderate-vigorous intensity physical activity [4].

Children involved in organized activities spending only 30% of the time in moderate intensity or more during a typical extracurricular session are often not reaching the physical activity guidelines throughout the week [5].

The ability to monitor one's intensity via technology could potentially motivate children to stay within the most beneficial intensities [6]. A whole body of evidence suggests that technologies provide stimulation for children and in turn, they are spending immense amounts of time using technology [7,8]. Children aged 8-10 years spend approximately eight hours per day using technology [9]. Health tracking devices have become more prevalent in society, even for children [10]. These devices provide feedback when performing physical activities and may increase a participant's motivation [11]. For example, studies have shown when adolescents have constant access to physical activity trackers, their running distance, energy expenditure, and time spent in moderate to vigorous intensity increases [10,11]. However, to the best of our knowledge, only one study has used a similar technology of instant feedbacks to increase time spent at moderate intensity or higher [12]. This study was conducted in Australia and had children aged 11-13 years wear a HR monitor during their physical education classes. One group of children had constant access to feedback for 5 weeks via a Polar HR watch, and the control group did not. After each class, the children were asked to estimate how many minutes they spent in moderate to vigorous intensity and both groups were unable to estimate the number of minutes adequately. This shows that intensity perception is a difficult concept for children to understand [1,10,12]. While several studies have looked at the effect of wearable biofeedback devices with adolescents, to the best of our knowledge there have been no studies looking at the effects of biofeedback on intensity in young children. This may be because the literature suggests children do not develop cognitively and struggle to understand incoming stimuli at a young age [12]. However, even adolescents struggle to identify intensity using wearable devices, and there is a wide array of devices being targeted towards youth as they spend large quantities of time using technology [9,12].

The main objective of this study was to determine if children, as young as 5 years of age, would perform at moderate intensity or above for a longer period when receiving feedback of their intensity via a color-coded projection on the wall compared to children not having feedback in the same session. We also aimed to explore if children's physical characteristics were associated with the average percentage of maximal HR reached during sessions.

Methods

Overview

Children between the ages of 5 and 11 were recruited through a local active play program lasting 12 weeks in which children engaged in 60 minutes of physical activity per session for 2 evening per week. Active play is defined as a form of gross motor or total body movement in which young children exert energy in a freely chosen, fun, and unstructured manner [13]. The current program was designed to engage children in the simple pleasures and benefits of regular physical activity, with a variety of fun interactive and noncompetitive physical activities intended to foster self-esteem, confidence, a positive self-image and the joy of being physically active. The program included games such as tag, "red light green light" and "fishes and whales." These games include sprinting, switching direction, and starting and stopping. The program was semistructured so the coaches had games planned but free play with ropes, balls and other gym equipment was always an option for the children, as well as suggesting alternative activities.

The Intervention

Before every session, the research assistant would open an envelope identifying which participants were selected to wear a HR monitor. This was selected randomly using the select case function in the statistical software SPSS (International Business Machines Corporation, New York, United States). If a participant missed a session, the randomization was postponed for the next session.

Participants were asked to wear a HR monitor, attached around their chest, for 4 sessions out of the 15 sessions offered. However, they only received feedback for 2 of the 4 sessions during which they wore a HR monitor. For the 2 sessions where participants received feedback, their HR was displayed on a wall in the gym. This method was used rather than a wearable monitor to create a group experience and encourage all the children to be "green" indicating they had all reached moderate intensity. The wall made it easy for the children to monitor their heart rate and for the researchers to explain the concept to the children. Each child was associated with a number to ensure anonymity, and their goal was to maintain their HR at moderate intensity (70% of maximum HR [14]) as indicated by displaying the number in green. Displaying the number in red indicated that their HR was below moderate intensity. For the other 2 sessions, the participants wore the equipment but did not receive feedback. The participant's response to feedback was analyzed on a per session basis to account for the variability in the session's activities. Parents signed a consent form and children signed an assent form before the study began. A research ethics board approved this project.

Measuring the Children's Characteristics

Children's anthropometrics, handgrip strength, body composition, cardiorespiratory fitness, and physical activity levels were measured to assess if these characteristics were associated with the average percent of maximal HR the children reached during the 4 sessions.

Anthropometrics measures and grip strength were collected to describe the sample of participants according to the Canadian Society of Exercise Physiology Protocol. These were obtained during 1 of the sessions when the participants were not wearing any equipment. Height was measured to the nearest 0.5 cm using a SECA stadiometer (SECA, Hamburg, Germany) and body weight was measured to the nearest 0.1 kg on a SECA model number 213 calibrated column scale. Waist circumference was taken with an anthropometric tape and measured to the nearest 0.5 cm at the upper lateral border of the iliac crest after the participant had crossed their arms over their chest [15]. Grip strength was measured with a hand dynamometer as the participant held the grip between their fingers and the base of their thumb. Two trials were performed on each hand, and the highest score of all trials was entered and analyzed.

Participants' body compositions were estimated using the Bod Pod (Cosmed, Concord, California, United States.). The Bod Pod was calibrated following standard protocol [16]. The participants wore minimal clothing and a bathing cap while sitting still in the Bod Pod. The thoracic gas volume was estimated, and the Brozek equation [17] was used to estimate the fat mass and muscle mass.

Cardiorespiratory fitness was estimated using the 20-meter shuttle test [18]. As per protocol, children ran between 2 lines 20 meters apart reaching the line before the sound of a beep. Every minute the participants were required to increase their speed by 0.5 km/h [18]. The children were first given a warning when they did not reach the line on time and eliminated after the second consecutive time. Cardiorespiratory fitness was estimated using a published equation developed for this population [19].

Finally, participants were asked to wear an SC-StepRx pedometer (StepsCount Inc, Deep River, Canada) for 7 days to capture steps per day and time spent in moderate-vigorous intensity. Intensity was estimated based on cadence thresholds: 110 for moderate and 130 for vigorous [20]. Children were given the pedometers on a Tuesday or Thursday after the exercise session and were asked to give it back after the session on the following week. Therefore, the information included sessions in the program. A minimum of 4 days of wear time was required to be included in the analysis. Averages were used to control for varying durations in wear time.

Statistics

Due to the small sample size, nonparametric tests were used. Nonparametric Mann-Whitney *U* tests were performed between the children's average percentage of maximal HR while having feedback and the children's average percentage of maximal HR while not receiving feedback for each session. The Spearman rank correlation between the individual's average percentage of maximal HR during all 4 sessions and participant's characteristics was computed.

Results

The Projected System

Feedback was provided by showing a display on a wall (see Figure 1). The children knew their identification number, and their heart rate was color-coded to indicate their intensity. They understood that green was the optimal zone and red meant they were below optimal intensity and if they worked harder they would reach the green zone.

The Children's Characteristics

The median age was 7 years, with slightly fewer boys (9/20, 45%) than girls (11/20, 55%) participating in the study (see Table 1). The median daily steps per day were 12,051 steps per day and 276.6 minutes in that week was spent in moderate to vigorous intensity.

No significant relationships were found (P>.05) between the participants' average percent of maximal HR reached during the active play sessions and the measured participants' characteristics (see Table 2).

The Intervention

No significant difference (P=.93) between the average percentage of maximal HR of the participants who received feedback and the average percentage of maximal HR of participants who did not receive feedback during the recorded sessions, with an effect size of –0.004 standard deviation units (see Figure 2). The x-axis represents the session in which data was recorded, and the children's average percent of maximal HR based on their estimated maximal HR is plotted on the y-axis. Nonparametric independent *t* tests were used to determine that there was no significant difference (P>.05) between the feedback and nonfeedback group for all 15 sessions. The groups were compared on a session by session basis to control for the variability of each session. This ensures the feedback and nonfeedback group were engaging in the same activities. The median percentage of HR max during all sessions was 71%, and 13/20 (65%) children had an average of 70% of their HR max for all sessions.

Figure 1. The projected system used to display biofeedback to the children.

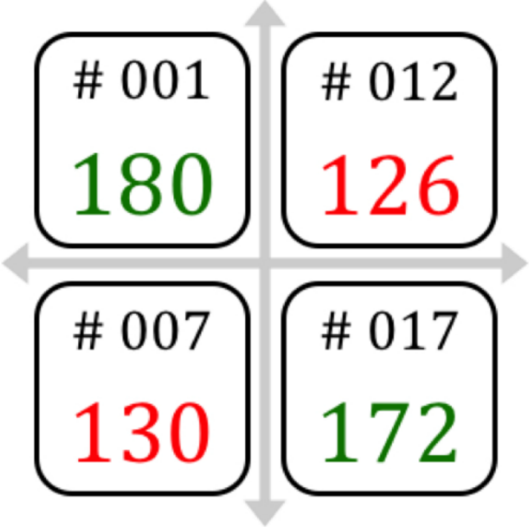

Table 1. A summary of the children’s characteristics (N=20).

Characteristics	Value
Age (years), median (IQR[a])	7.0 (6.0-8.0)
Gender, n (%)	
Male	9 (45)
Female	11 (55)
Estimated VO_{2max} (mL/kg/min), median (IQR)	44.4 (43.5-48.0)
Height (cm), median (IQR)	130.0 (127.0-133.5)
Weight (kg), median (IQR)	25.9 (24.5-33.8)
Waist circumference (cm), median (IQR)	61.0 (56.0-67.5)
Grip strength (kg), median (IQR)	11.0 (8.0-13.0)
Fat mass (%), median (IQR)	21.6 (16.7-27.7)
Average daily steps[b], median (IQR)	12,051 (9,649-15,106)
Weekly MVPA[c] (min)[b], median (IQR)	276.6 (197.4-356.1)

[a] IQR: interquartile range.

[b] N=9.

[c] MVPA: moderate-to-vigorous physical activity.

Table 2. The relationship between the children’s percent of maximum heart rate and their characteristics using the Spearman rank correlation (ρ).

Characteristic	ρ	*P* value
Age (years)	.27	.26
Weight (kg)	.19	.44
Height (cm)	.30	.21
Waist circumference (cm)	.058	.82
Grip strength (kg)	.055	.82
Fat mass (%)	–.022	.93
Physical activity level	–.18	.58
Fitness level	–.096	.69

Figure 2. The association between the median percentage of maximal heart rate with and without feedback.

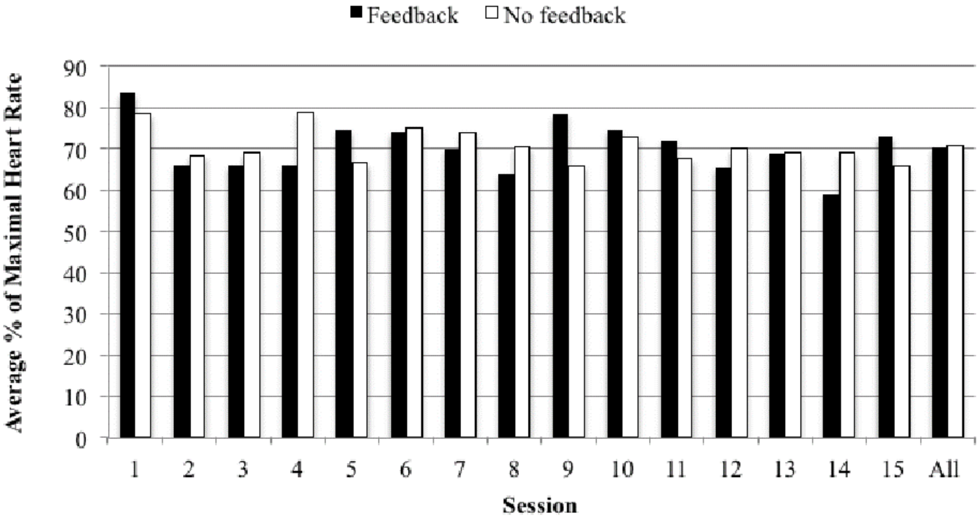

Figure 3. The proportion of time spent at moderate intensity or greater for all sessions. MPVA: moderate-to-vigorous physical activity.

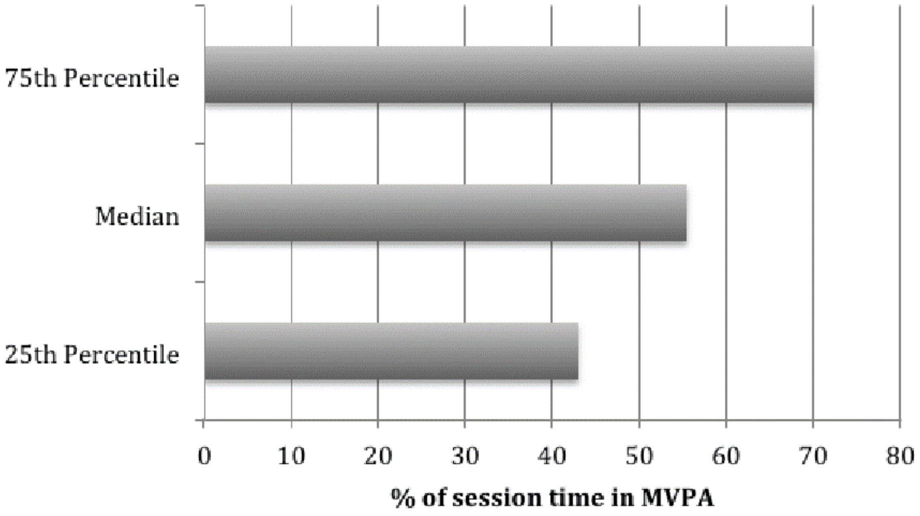

Figure 3 displays the median proportion of time spent in moderate-vigorous intensity during the recorded sessions. This includes all 15 sessions with data collected from 20 children each wearing a heart rate monitor 4 times, twice with feedback and twice without feedback. Therefore, illustrating the time children spent engaging in moderate-to-vigorous physical activity (MVPA) during the active play program regardless of biofeedback. The median proportion of time spent in MVPA during all active play sessions was 20.5 minutes, representing an average of 55.5% per session.

Discussion

Principal Findings

The main objective of this study was to determine if children, as young as 5 years of age would spend more time at moderate to vigorous intensity when receiving feedback of their intensity via a color-coded HR projected onto a wall compared to children not receiving feedback in the same session. Although 55.5% of the time was spent at moderate intensity or above, the present findings indicate that when young children are receiving instant feedback during active play, they were not spending more time in MVPA compared to those who are not receiving feedback. We also aimed to explore if children's physical characteristics were associated with the average percentage of maximal HR reached during the sessions. The participants' characteristics were not significantly associated with the average percentage of maximal HR they reached during the 4 monitored active play sessions.

The ability to identify exercise intensity is a complex task for anyone including children [12,21,22]. The median age of the participants involved in this study was 7 years. Their age may have contributed to their inability to perceive the intensity as previous research has suggested that children do not develop the ability to logically interpret surrounding stimuli, until 11 years of age [12,23]. Therefore, it is possible that children involved in this study did not have the cognitive ability to interpret and respond to feedback related to the exercise intensity, despite the extensive time young children now spend using technology. A study by Gaudet et al [10] reported that the Prochaska's stages of change were influencing the ability to be receptive to feedback and do more activity at moderate intensity with adolescents when in the stage of action. The participants' stage of change in the current study is unknown and should have been asked of the children and their parents. The children in this study were also quite active based on their daily step count, averaging more than 12,000 steps per day. It is possible that different results would have been observed in a curriculum instead of during an after-school program that tends to attract active kids [5]. Even if the feedback was not associated with greater intensity, it is important to note that 55.5% of the sessions were spent at the moderate-vigorous intensity. This is important because most traditional physical education classes report [24] that the average is only 39.4% for boys and 29.1% for girls in physical education classes. Additional studies [25] have shown that young children enjoy physical activity more when the activity is noncompetitive, and there is a choice involved compared to structured activities. Potentially, enjoyment contributed to the children reaching an average of 70% of their maximal HR regardless of whether they were receiving feedback.

Of the characteristics that were measured, none were associated with the average percentage of maximal HR reached during sessions, regardless of feedback or not. Regarding body weight, it seems that intensity was not influencing the reached intensity during sessions when performing the active play. This result is similar to a study conducted with children aged between 6 and 9 years that found that nonobese and children living with obesity had similar heart rates during active play sessions [1]. Prior research has shown that children living with obesity perceive themselves to be less competent than their peers, and would feel more comfortable engaging in active play than in a structured athletic setting [1].

Children are often more active during physical education classes if they have a high ability level and low body mass index [24]. Since the participants' physical characteristics did not affect the children's average intensity, perhaps active play should be encouraged in different settings to increase fitness level.

Limitations

There were some limitations to this study. First, this study used a small sample size. The children were also young, considered active and were voluntarily attending the program. While the activity sessions were an hour in length, the children's heart rates were only recorded for an average of 37 (SD 4) minutes. Second, the sample was not randomized, and a crossover design was not used. Each session was different. This means that the children did not necessarily engage in the same activities when they had or did not have feedback. The children receiving feedback were not isolated from the children not receiving feedback. Therefore, the children not receiving feedback may have been mirroring the intensity of the children who were receiving feedback. However, physical activity was objectively measured using blinded pedometers. The color-coded projection on the wall was novel for the children and the active play program allowed for a well-supervised physical activity intervention.

Conclusions

Providing instant feedback about their intensity for children with an average age of 7 years does not significantly increase their intensity when engaging in an active play session. However, it is important to note that during the active play sessions, children spent 55.5% of the time at moderate to vigorous intensity. Further research should examine the effects of providing feedback on exercise intensity when performing active play with older children with a broader range of physical activity levels.

Conflicts of Interest

None declared.

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Abbreviations

HR: heart rate
IQR: interquartile range
MVPA: moderate-to-vigorous physical activity

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Original Paper

Online Peer-to-Peer Mentoring Support for Youth with Hemophilia: Qualitative Needs Assessment

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Abstract

Background: To support adolescents through transition from pediatrics to adult care, health care providers and families help teens gain knowledge and develop self-management skills. Peer mentoring can provide meaningful support and has been associated with improved health outcomes in patients with other chronic conditions. Peer mentoring is an appealing way to provide support, but it is imperative to consider the unique needs of adolescents to ensure its success.

Objective: The objective of our study was to identify the peer mentoring wants and needs of youth with hemophilia in order to guide the development of a new program.

Methods: In this qualitative study, we interviewed a convenience sample of youth with hemophilia from 2 Canadian hemophilia treatment centers. Two iterative cycles of audiorecorded, semistructured individual interviews were conducted. Descriptive statistics and content analyses were used to organize data into categories that reflected emerging themes.

Results: In total, we recruited 23 participants aged 12-20 years, with a mean age of 14.91 (2.57) years. When asked about program design, participants weighed the importance of flexibility in delivery (eg, Web-based, in person, text messaging [short message service]), content (eg, structured vs unstructured), frequency of sessions, and length of the program. Participants identified some potential challenges such as scheduling issues, comfort level for disease discussion, and discordant mentor-mentee personality types. The program was viewed as a positive medium for connecting peers with hemophilia.

Conclusions: Adolescents with hemophilia expressed interest in a peer mentoring program and provided valuable insight that will be applied in the development of a peer mentoring program for youth with hemophilia.

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KEYWORDS

hemophilia; adolescents; transition; self-management; education; internet; mentoring

Introduction

The challenges of transition of care for young people with hemophilia have been documented and well reviewed [1-3]. As the responsibilities of disease management shift from caregivers to patients themselves, adolescents are expected to gain knowledge and self-management skills to become independent. Despite well-developed resources for North American hemophilia care providers [4-6], adolescents and young adults report gaps in the understanding and skills [7-9].

Recently, a pilot study suggested that a Web-based learning program is an effective tool for providing education and self-management skills to youth with hemophilia [10]. Following completion of the program, adolescents made significant gains in knowledge, self-efficacy, and readiness for transition of care from caregivers to self. One aspect of the program that was highly rated by adolescents was the support gained from a trained "health coach," who made weekly telephone calls to discuss their progress and answer their questions. Although this element was popular with adolescents, providing this one-on-one support is challenging as it requires significant ongoing resources.

Peer mentoring support in health care is an explicit form of social support established to provide individuals with emotional (eg, expressions of caring, empathy, and reassurance), appraisal (eg, affirmation of one's feelings and behaviors, encouraging persistence for conflict resolution, and reassurance that frustrations can be handled), and informational (eg, providing advice, suggestions, and facts relevant to issues with which the peer is dealing) support from other people living with similar conditions [11]. Peer mentoring can provide meaningful social support and has also been associated with improved health outcomes [12-15]. In qualitative interviews, some adolescents with hemophilia expressed feelings of isolation and voiced interest in obtaining peer support; older adolescents and young adults felt that peer support was valuable and expressed a desire to mentor younger youth [7].

A promising Skype-based peer mentoring support intervention (iPeer2Peer Program; iP2P) has been piloted in youth with arthritis and chronic pain. The program sex matched young adults (mentors) who had successfully transitioned to adult care with adolescents aged 12-18 years (mentees), and they completed 10 Skype calls over an 8-week period. When compared with a waitlist control group, youth demonstrated improvements in self-management and pain-coping efficacy immediately after completing iP2P [16,17]. As arthritis and chronic pain affect more females than males, only a few males participated in the study. Given that hemophilia is X-linked, it is important to explore whether an adaptation of the iP2P program would enhance the self-management and transitional care in this population.

In order to explore the need for and acceptability of an iP2P peer mentorship program for youth with hemophilia, we conducted a needs assessment with qualitative interviews. The aims of the needs assessment were to (1) document the perceived self-management needs of youth with hemophilia, (2) determine if Web-based peer mentoring is an acceptable means of learning self-management strategies, and (3) gather information on youth preferences and ideas for an optimal Web-based mentoring program, if developed.

Methods

Participant Recruitment Strategy

A qualitative descriptive study using semistructured individual interviews was conducted in 2015-2016 with adolescents and young adults living with moderate or severe hemophilia from 2 tertiary hemophilia treatment centers (HTCs) in Ontario (The Hospital for Sick Children, Toronto, and McMaster University Medical Centre, Hamilton). A purposive sampling method was used based on age to maximize the variability of the sample. Eligibility inclusion criteria included adolescents and young adults who were (1) between 12 and 25 years old, (2) diagnosed with moderate or severe hemophilia, (3) able to speak and comprehend English, and (4) willing and able to complete an in-person or telephone interview. Exclusion criteria included (1) a significant cognitive delay and (2) major comorbid illnesses (medical or psychiatric). The age range was chosen to foster "near peer" relationships between potential mentors and mentees. The eligibility was determined upon review of the local patient database by the clinical team. Research ethics boards at both hospitals approved the study.

Interview Protocol

Once informed consent was obtained, participants completed demographic questionnaires. Interviews followed a semistructured format using an interview guide developed by the study team based on clinical experience and current research literature. Participants were asked about their experiences living with hemophilia, their interests in meeting other youth with hemophilia, and being involved in a Skype-based peer mentoring program, as well as the features they would want in a new program (eg, frequency, length, and content).

Statistical and Qualitative Analyses

Descriptive statistics were used to summarize sample characteristics. Audiotaped interviews were transcribed verbatim and verified against the audio recordings and notes taken during the interviews. Transcribed data were imported into NVivo 10 [18]. Under the supervision of a coinvestigator (JNS), the analyses were conducted independently by two members of the research team (SL, CN) and two research students using simple content analyses, as outlined by Sandelowski [19]. The study team reviewed a subset of the transcripts, and preliminary themes were used to develop and revise the coding scheme through discussion. To ensure the coding scheme was grounded in the data, raw data were revisited throughout the analytic process [20]. Interrater reliability analyses were conducted to establish agreement between coders.

Results

Study Participants

Across the 2 tertiary HTCs, 56 patients were approached. Of those approached, 28 patients declined due to lack of interest in the study and 28 patients were consented and enrolled.

However, 5 participants were lost to follow-up during the interview phase (ie, could not be contacted via telephone or email); thus, 23 participants completed the study. Demographic characteristics for the adolescent and young adult sample are summarized in Table 1.

All 23 participants had a computer at home with internet access. Of all, 56% (13/23) participants spent over 7 hours on the internet and 47% (11/13) spent over 7 hours on the computer each week. All participants reported being “comfortable” or “very comfortable” using the computer and the internet. Computer usage data were missing for 2 participants.

Thematic Analysis for Disease Impact

Thematic analysis revealed five major disease impact themes: physical, emotional, social, school and work, and the future. Major themes and key quotes from participants are summarized in Table 2.

Thematic Analysis for Program Development

Participants were asked for their opinions about a mentorship program for adolescents with hemophilia. Thematic analysis revealed six major themes for program development: content, delivery, frequency, length, potential challenges, and anticipated benefits. We have summarized major themes and participant comments.

Content

Participants described wanting mentorship on the challenges of living with hemophilia, including different treatments, self-management experiences, and sports participation. Opinions differed on whether conversation should be guided by pre-set questions or be unstructured. For example:

> *I think it should really be whatever you want to talk about because if it is structured, then it’s more like a robot interaction...but if you personalize it you make it more free-flowing then...it accomplishes more.* [Age 14]

Most participants agreed that the mentorship relationship should begin by discussing general topics and then progress with more personal topics, as mentees grew more comfortable with the mentor where trust and rapport had then been developed.

Table 1. Demographic characteristics of the adolescent and young adult sample.

Characteristic	Adolescents and young adults (n=23)
Sex, n (%)	
Male	23 (100)
Female	0 (0)
Age, mean (SD)	14.91 (2.57)
Current level of education[a], n (%)	
Grade 7	6 (26)
Grade 8	3 (13)
Grade 9	2 (9)
Grade 10	1 (4)
Grade 11	4 (18)
Grade 12	3 (13)
University	1 (4)
College	1 (4)
Ethnicity, n (%)	
White	15 (64)
Black	2 (9)
Japanese	1 (4)
Latin American	1 (4)
South Asian	1 (4)
South East Asian	1 (4)
Other	2 (9)
Do not want to answer	0 (0)

[a] Data related to current level of education is missing for 2 participants.

Table 2. Impact of hemophilia on teens and young adults.

Disease Impact	Major Findings	Exemplar Quotes
Physical	• Impact of pain associated with bleeds and with regular venipuncture • Some perceived minimal physical impact largely because hemophilia is easily treated by prophylactic treatment • Some learned about physical risks through individual experiences and seeking information from their health care team, family, or friends with hemophilia	*Well its actually been quite a challenge, always getting needles probably like every Tuesday and Thursday...it's been kinda difficult. [Age 12]* *I sprained my ankle when I was in grade 4...[that joint] started to bleed a lot...there was more risk involved, like cartilage problems [and] like chronic pain...which is not something that would easily happen to someone without hemophilia because it clots. [Age 14]* *Well, luckily, I did have an older brother and I did learn a bit from his mistakes, but I mean obviously, you want to try things. [Age 17]*
Emotional	• Main cause of emotional upset was not being able to play sports or having to miss out on activities or extracurriculars	*It's impacted my life a lot, sometimes it's hard to deal with. I can't play any contact sports, and sometimes seeing your friends playing sports...it's definitely an experience, but you do learn to deal with it. [Age 17]* *Everyone kept telling me...you're very fragile, in fact, when I was a kid, I felt more like a glass vase...because I was afraid that I would break out to a bleed. [Age 18]* *I can't really do much...like...a lot sports, like hockey or football, because if I get hurt really badly I would end up in the hospital. [Age 12]*
Social	• Inability to participate in certain activities limited social interaction with friends • Feelings of isolation because participants did not feel comfortable explaining their condition to peers • Having hemophilia gave some participants an opportunity to create strong bonds with family members and peers who have the same condition	*Probably the only one big challenge that I have faced is like doing stuff with friends. Like sometimes friends are doing stuff that I wouldn't participate in and it would feel a little bit sad...I just kind of accepted it and my friends have been really understanding about it. [Age 14]* *You felt sometimes you didn't want to tell people if you had it...you didn't want people to treat you differently...I kind of kept to myself when I was really young. [Age 20]* *I have a younger brother he also has hemophilia. We connected [and] it was great...With my parents...I got to see how caring they were. They were out almost all day out at the hospital rooms or emergencies all the time. [Age 20]*
School and Work	• Majority felt having hemophilia did not impact their school attendance, as teachers were accommodating and supportive, but some decreased their participation in physical education due to risks • Of those currently employed, most did not disclose their condition as they felt it did not interfere with their position and there was no high risk of injury at work	*Well in school, in gym, sometimes I have to skip out on some of the activities, because they're a little too...rough for me to play. [Age 14]* *Yea, my boss knows I have hemophilia, she understands what's happening, she's you know um, considerate about it, she understands I won't be able to work for a while. [Age 17]*
Future	• Most did not envision hemophilia having an impact on their career path, aside from avoiding physically demanding careers • Expressed a need to choose postsecondary institutions where easy access to medical services was available • No major concerns about hemophilia affecting future romantic relationships or having children	*I'm pretty sure it won't affect my future career, but it could limit my career, like since I can't do much, most of the hard work. [Age 17]* *Going to the future...if I do have kids, you know the females would be carriers and the males would be unaffected that's fairly okay. I don't mind passing on the gene. I could deal with that. [Age 20]*

Delivery

Participants varied in their preferences of delivery method of mentorship (eg, in person, Web-based, or telephone or texting). In-person mentorship sessions were felt to be most convenient if they were held on the same day as a regular clinic appointment. Web-based mentorship (eg, Facetime or Skype) was viewed as convenient for several reasons, including not having to rely on anyone for transportation, for individuals who live far away from the hospital, and the flexibility to schedule sessions at convenient times and minimize scheduling conflicts. Participants also reflected that they might also be more willing to open up to someone online, rather than in person. Some participants mentioned texting as a good option for those who did not like face-to-face interactions; however, others indicated that it would be difficult to connect with their mentors solely through texting. There were also varying opinions about individual versus group-based mentorship. Some participants stated that they would feel intimidated and uncomfortable sharing personal information in a group, even on an online group forum. However, others saw value in hearing from a group to obtain a broader perspective and stated that it would increase the likelihood of connecting with peers in the group. One teen stated the following:

> *I think both are good. Both have pros and cons. Um if it is a group discussion, I don't think they would be sharing that much information about private stuff though but uh depends on the person. But I think most people will probably like one-on-one.* [Age 20]

Frequency

Participants' preferences for the frequency of mentoring sessions ranged from twice a week to bimonthly. Some participants preferred not to have scheduled sessions, but rather only have sessions as needed. Some felt they would find comfort in knowing that they could have a mentor to reach out to when needed. Some participants indicated that the frequency of sessions would depend on whether sessions were held in person or were online. A teen said the following:

> *I would say once a week or, if it was at my home, probably twice a week. Just because [the hospital] is a commute every time to get there.* [Age 13]

Length

Participants also indicated a range for length of sessions, from 5 minutes to 2 hours. Some participants indicated that they preferred not to have a time constraint placed on them, but rather have the session be as short or as long as they needed. A participant said the following:

> *I think it all just depends on the person themselves...whether they have a lot of questions or not, I guess the ideal time would be around 20 minutes...longer if they have more questions.* [Age 17]

Potential Challenges

When asked, only a few participants could list the potential challenges to the feasibility and uptake of a peer mentoring program (Table 3).

One potential challenge was shyness or lack of openness among mentees. Participants were also worried there might be a personality clash or difficulty establishing a connection with the mentor. Some participants were concerned that mentees would not know how to ask the right questions and that finding experienced individuals to fill the mentor role may be a challenge.

Another challenge related to a group-based mentorship program was a concern about hearing about other teens' struggles and problems. Some thought that this would pose an unnecessary burden on them. Timing of the program was also seen as a challenge, with participants generally preferring to have a mentor at an age when they are starting to take on more disease self-management responsibilities or struggling to manage symptoms or treatment.

Anticipated Benefits

When asked about the possible benefits of receiving mentorship, one of the biggest perceived benefits was feeling like they are not alone in their disease. They indicated that participating in a mentoring program would help them feel being part of the hemophilia community and gain a sense of hope seeing someone with hemophilia succeeding in adulthood. Older participants expressed an interest in being a mentor as they felt confident in their ability to manage their condition independently.

Table 3. Challenges of a peer mentoring program for adolescents with hemophilia.

Challenges	Exemplar quotes
Connection	
Issues establishing rapport between mentors and mentees (eg, shyness, comfort level, personality)	*[What if a] mentee just doesn't feel like a connection to the person that they're talking to, they don't open up to them, or if the child doesn't know what questions to ask the peer mentor. [Age 17]*
Timing of program delivery	
Prefer to access program when starting to take on more disease self-management responsibilities or struggling to manage symptoms or treatment	*It helps little kids to prepare for like, how to do their needles, or to prepare for how it's going to affect their life later on in the future. [Age 14]*
Scheduling	
Difficult to find a time when all parties are available; especially difficult if sessions occur in person or in a group setting	*I guess finding the time to all meet up and all that. If it's just like a big group. [Age 13]*
Time commitment	
Full schedule of extracurricular activities make it difficult to find time to fit in another activity	*People have to do a lot of things...time is on the shortage most of the time, most people don't have enough time to like get to other people. [Age 17]*
Slow enrollment	
Concerns about finding enough adolescents to participate due to lack of interest	*But I guess just trying to get the kids interested...I think that would be hardest part, having kids actually want to...participate without them having it enforced upon them. [Age 20]*

Table 4. Benefits of a peer mentoring program for adolescents with hemophilia.

Benefits	Exemplar quotes
Sense of community	
Feeling like they are not alone in their disease	*I think [the mentorship sessions] would make kids more open about hemophilia...talk about it, talk to their friends about it. Making them feel like they're not alone you could say like they're not the only ones. Inclusion. [Age 20]* *People really having a sense of community about their hemophilia because alone we are just hemophiliacs but together we are a social group, we are a community that's helping one another. [Age 14]*
Sense of hope	
Mentor success in adulthood	*They'll also feel like there's someone in the same boat as me...cause you almost feel isolated, when no one else has it...So if they have someone to talk to...[they look] forward to the future and it's not just going to be a boring future. [Age 17]*
Opportunity for discussion	
Speak about hemophilia from a nonmedical perspective; focus on aspects of daily life	*Well, I would, like, learn a lot through someone that is more skilled, who would understand more than I do. [Age 12]*
Ease of dialogue	
Extension of attending hemophilia summer camp; easier to speak to someone of a similar age and diagnosis	*Definitely just someone to talk to about hemophilia would awesome because you can just talk to them about things in your life that are affected by hemophilia...you can relate to them because they've gone through what you've been through. [Age 14]*

Many participants made reference to attending a hemophilia summer camp and saw the mentoring program as a welcome extension of the camp. Most participants also indicated that it would be easier to speak to someone with a similar age and diagnosis. Some participants indicated that they would find the mentoring sessions helpful because they would have the opportunity to speak about how hemophilia has affected their lives and to ask for advice about hemophilia management and about impact of hemophilia on other aspects of typical teenage life. A summary of perceived benefits of a mentoring program is shown in Table 4.

Discussion

Not surprisingly, our subjects reported that their hemophilia has had significant effects on the physical, emotional, and social aspects of their lives. The challenges of activity or sports restrictions permeated this dialogue, suggesting this to be the most significant stressor facing our young people. Other voiced challenges involved feelings of isolation and discomfort among participants related to disclosure of their condition. These results were similar to those of previously published studies [9,21], suggesting that these issues are universal and reinforcing the areas in which young people with hemophilia require support.

In addition to common challenges, our participants shared a strong interest in gaining support through mentorship from more experienced individuals who were living with the condition. Many discussed their experiences at hemophilia camp as a time when they met others and received support. Thomas and Gaslin described the importance of such camps as means to improve self-esteem in young people with hemophilia [22]. In addition, a recent systematic review suggested that participation in the camps had therapeutic effects on the aspects of health-related quality of life [23]. Discussions with our subjects about the benefits provided by hemophilia camp support an expansion of available mentorship to include youth that are not able to attend summer camp, as well as to extend the supports gained through camping programs into the school year through an alternative program.

In preparing to develop a new mentorship initiative, we recognized the value of asking for input from potential mentees and mentors prior to building the program. We used the interview platform to determine participants' views on peer support and the acceptability of Web-based mentorship. Further areas of the program can be explored in future studies (eg, age preference of mentors, life experiences). While we recognized that published data have shown this to be a feasible and satisfying approach for patients with other chronic conditions [17], we wanted to ensure that this approach could be applied to our patients with hemophilia and tailored it to their specific needs as necessary. No formal comparison has been made between the needs of patients with hemophilia and those with other chronic conditions where a peer mentorship program has been piloted [16,17]. We anticipate that the needs of patients with hemophilia would be different due to the condition being present at birth, which may impact their perspectives and management of their conditions. In addition, treatment options vary across populations.

The limitations of this study include a relatively small study population in 2 proximal centers. The sample size was small, but in keeping with an appropriate size for this qualitative methodology [24]. Content themes were saturated, suggesting that central issues were identified. Although the results may not be completely generalizable, significant insight has been provided into the thoughts and experiences of young people with hemophilia. Although a purposive sampling method was used, there is a potential for selection bias in favor of youth who are either motivated to participate or interested in a peer support program. The invitation to participate was extended to all eligible participants, and the decision to partake was voluntary.

In summary, it is essential to consider end-user needs and preferences prior to developing support programs to ensure that we meet the needs of our patients. While our participants generally supported Web-based peer mentorship, our data suggest that there is no one-size-fits-all approach that will meet the needs of adolescents and young adults with hemophilia. Through the data obtained, we were able to catalogue the perceived needs of this patient population and document its preferences and opinions on how best to develop a Web-based mentoring program. Moving forward, we will aim to build a program that is flexible and teen driven with a supportive backbone of education and social supports.

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Authors' Contributions

SAK led the development of the initial research design, with inputs from VRB, VB, and JNS. Data collection was supervised by SAK and performed by CN and SL. All members of the team finalized the qualitative analysis. Paper was written primarily by VRB and revised by all authors prior to submission.

Conflicts of Interest

None declared.

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Abbreviations

HTC: hemophilia treatment center
iP2P: iPeer2Peer Program

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Original Paper

Exploring the Needs of Adolescents With Sickle Cell Disease to Inform a Digital Self-Management and Transitional Care Program: Qualitative Study

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Abstract

Background: Accessible self-management interventions are critical for adolescents with sickle cell disease to better cope with their disease, improve health outcomes and health-related quality of life, and promote successful transition to adult health care services. However, very few comprehensive self-management and transitional care programs have been developed and tested in this population. Internet and mobile phone technologies can improve accessibility and acceptability of interventions to promote disease self-management in adolescents with sickle cell disease.

Objective: The aim of this study was to qualitatively explore the following from the perspectives of adolescents, parents, and their health care providers: (1) the impact of sickle cell disease on adolescents to identify challenges to their self-management and transitional care and (2) determine the essential components of a digital self-management and transitional care program as the first phase to inform its development.

Methods: A qualitative descriptive design utilizing audio-recorded, semistructured interviews was used. Adolescents (n=19, aged 12-19 years) and parents (n=2) participated in individual interviews, and health care providers (n=17) participated in focus group discussions and were recruited from an urban tertiary care pediatric hospital. Audio-recorded data were transcribed verbatim and organized into categories inductively, reflecting emerging themes using simple content analysis.

Results: Data were categorized into 4 major themes: (1) impact of sickle cell disease, (2) experiences and challenges of self-management, (3) recommendations for self-management and transitional care, and (4) perceptions about a digital self-management program. Themes included subcategories and the perspectives of adolescents, parents, and health care providers. Adolescents discussed more issues related to self-management, whereas health care providers and parents discussed issues related to transition to adult health services.

Conclusions: Adolescents, parents, and health care providers described the continued challenges youth with sickle cell disease face in terms of psychosocial impacts and stigmatization. Participants perceived a benefit to alleviating some of these challenges through a digital self-management tool. They recommended that an effective digital self-management program should provide appropriate sickle cell disease–related education; guidance on developing self-advocacy and communication skills; empower adolescents with information for planning for their future; provide options for social support; and be designed to be engaging for both adolescents and parents to use. A digital platform to deliver these elements is an accessible and acceptable way to address the self-management and transitional care needs of adolescents.

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KEYWORDS

sickle cell; adolescent; cell phone; self-management; internet; qualitative research; needs assessment; transitional care

Introduction

Sickle cell disease (SCD) is an inherited red blood cell disorder that predominantly affects individuals of African descent. Increased prevalence is also seen in Mediterranean, Caribbean, South and Central American, Arab, and East Indian populations [1]. SCD is caused by a genetic mutation that results in abnormal hemoglobin, which makes blood cells rigid and sickled in shape. These abnormal red cells can disrupt the flow of blood in small vessels, resulting in hypoxia-reperfusion injury throughout the body and its organs, causing episodes of painful vaso-occlusive crises and organ damage. Cerebral infarcts resulting in neurological and neurocognitive deficits are the most feared complications [2]. Negative consequences from recurrent pain in SCD include academic underachievement related to school absenteeism, limited physical activity, symptoms of depression and anxiety, and disruption of interpersonal relations [3,4].

Despite the suffering and burden associated with SCD, minimal research has focused on promoting disease self-management among adolescents with SCD, such as teaching skills to help teens to cope with symptoms and manage their chronic illness. Many youth with SCD leave pediatric care without adequate transition preparation and subsequently do not successfully transfer to adult health care services [5,6], which may put them at risk for higher morbidity and earlier mortality during early adulthood years [5-7]. Therefore, improving health-related quality of life and ensuring successful transition to adult health care through better disease self-management is critical [5,6,8,9].

Self-management interventions such as information-based material and cognitive behavioral therapies (CBTs) for SCD have shown promise in symptom reduction and improved health-related quality of life [8,10,11]. However, the vast majority of adolescents with chronic health conditions do not receive comprehensive self-management (eg, CBT) education due to lack of access to these therapies. This limited accessibility is a function of the direct and indirect costs associated with therapy as well as limited availability of trained professionals, particularly in nonurban areas [8]. There is a clear need to develop accessible and acceptable ways to deliver self-management and transitional care therapies to adolescents with SCD and their families.

Information and communication technologies offer an accessible platform for the delivery of health interventions for patients and families [12-16]. Access to Web-based health interventions eliminates geographic constraints, allows for anonymity, and provides 24-hour access to disease-related information and self-management strategies that may help patients feel more in control of managing their health problems and minimize feelings of isolation [12,13]. Digital interventions are treatments based on effective face-to-face interventions (eg, CBT) that are transformed for delivery via the internet with the goal of improved health outcomes. Previous efforts in developing interventions for adolescents with SCD have focused on medication adherence, symptom tracking, and CBT for pain management [17-20]. However, many of these programs are characterized by limited involvement of adolescents and their families in their development.

To date, no digital, comprehensive self-management and transitional care program has been developed and evaluated in terms of improved health outcomes (symptom reduction and improved transition readiness and health-related quality of life) for adolescents with SCD. Thus, the aims of this study were to qualitatively examine the following from the perspectives of adolescents, parents, and their health care providers (HCPs): (1) examine the impact of SCD on adolescents to identify challenges to their self-management and transitional care and (2) determine the key components of a digital program for SCD self-management and transitional care for adolescents.

Methods

Patient and Parent Selection

Adolescents, parents, and HCPs were purposively recruited from 1 large metropolitan tertiary care pediatric center in Toronto, Canada. Adolescents were eligible to participate if they were (1) 12 to 19 years old, (2) diagnosed with SCD, and (3) able to speak and read English and at least one of their parents was able to speak and read English. Adolescents were excluded if they had (1) severe cognitive impairments or (2) major medical or psychiatric concurrent illnesses, which precluded assessment of their self-management and transitional care needs. Parents were eligible to participate if they were able to speak and read English.

Health Care Provider Selection

HCPs were eligible to participate if they (1) had worked in pediatric hematology, general pediatrics, and emergency medicine for at least 1 year at the time of the study and provided care to adolescents with SCD and (2) could speak and read English.

Study Design

A descriptive qualitative design with semistructured, audiotaped individual interviews with adolescents with SCD and parents, and focus group interviews with HCPs, were undertaken to examine the impact of SCD on adolescents; to determine self-management and transitional care needs of adolescents with SCD; and to inform the development of a Web-enabled self-management and transitional care intervention [21,24]. Individual interviews were utilized to gain an appreciation of the perspectives of the individual adolescents and their parents, uninfluenced by the views of others. Focus group interviews were conducted with HCPs to capitalize on communication and shared interaction to generate data and gain insight into specific issues in more depth [22].

Procedures

The local institutional research ethics board approved the study. The research assistant obtained consent, arranged an individual interview with each of the parent and adolescent participants, and asked them to complete questionnaires on demographics and on internet use. The research assistant completed a health information questionnaire to gather additional demographic and medical information from the adolescent's chart. The research assistant conducted the individual interviews with adolescents and parents. Interview questions were based on a literature review, followed by pilot testing with 2 to 3 adolescents with SCD and their parents, and modified based on their feedback (see Textbox 1 for semistructured interview guide). Interviews began with a broad introductory question, followed by questions and probes to allow participants to elaborate on their experiences. Refreshments and a small honorarium were provided to compensate for participant time.

HCP participants were recruited using posters describing the study and information sessions at the pediatric center. After obtaining consent from HCPs, a mutually convenient time was set up for the focus group interviews once 5 to 7 participants were enrolled. HCPs were also asked to complete a questionnaire on demographics. Trained members of the research team moderated the focus group discussions among the HCPs. During and immediately after the focus group discussions took place, the interviewer detailed field notes on their impressions of participant responses and the interviewing process. All individual and focus group interviews were audio-recorded and transcribed verbatim.

Data Analysis

All data from individual and focus group interviews and field notes were analyzed inductively using simple content analysis [23]. Transcribed data were managed using NVivo computer software program (QSR International). Demographic data were analyzed using descriptive statistics in Microsoft Excel and used to summarize the characteristics of the study participants. All data were read several times by 3 investigators (JNS, CN, and YK) to obtain an overall understanding, identify data codes, and ensure that all comments were carefully considered and included.

Textbox 1. Broad questions in semistructured interview guide.

1. Can you tell me what it has been like for you/your son or daughter/adolescents to live with sickle cell disease (SCD)?
2. What do you think is important to know and do so that you/your son or daughter/adolescents can learn or manage (or take care of) your/their SCD?
3. What do you/your son or daughter/adolescents need to know about your/their SCD?
4. What do you/your son or daughter/adolescents need to know about in terms of how to manage or treat your/their SCD?
5. What do you/your son or daughter/adolescents need to know about drugs and other treatments and how they affect you/them?
6. Can you tell me what it is like for you/your son or daughter/adolescents when you/they come to the emergency department for a sickle cell crisis?
7. Can you tell me about how SCD affects the other aspects of your/your son or daughter/adolescents' life?
8. What is it like (for your son or daughter/adolescents) to talk about your/their SCD to your/their doctors and nurses? Family? Friends? Teachers?
9. When you/your son or daughter/adolescents turn 18, you/they will be transferred from a pediatric hospital to an adult hospital. Have you thought about this? What do you think it will be like (for them)?
10. How do you think SCD will affect you/your son or daughter/adolescents' in the future?
11. How have you/your son or daughter/adolescents learned about your/their SCD and how to manage and treat it?
12. If you/your son or daughter/adolescents had to tell someone else about what it's like to have SCD and how to deal with it what would you/they tell them?
13. What do you think it would be like (for your son or daughter/adolescents) to learn more about your/their SCD from a web site made just for teens and young adults with SCD and their families?
14. Is there anything else you would like to tell us about what you think is important to know and do so that you/your son or daughter/adolescents can learn to take care of your/their SCD better?

As data were entered into the analyses, codes continued to be generated, until there were no new data that could not be categorized under existing codes. Codes were combined into higher-level themes, and the themes were checked against coded extracts and the entire dataset [23,24]. Disagreements were addressed through discussion and consensus of all investigators.

Results

Participant Characteristics

A total of 19 adolescents, 2 parents, and 17 HCPs were recruited from March 2012 to August 2012. Adolescents and parents individually participated in the semistructured interviews, and HCPs participated in focus groups. Participant demographics, medical information, and internet and computer use are summarized in Tables 1 and 2. HCP demographics information is summarized in Table 3. Of the 18 adolescents who responded to the internet and computer use questionnaire, 94% (17/18) had a computer with internet access and were either “comfortable” or “very comfortable” using the internet.

Self-Management and Transitional Care Needs

The perspectives of participants were categorized into 4 major themes: “impact of sickle cell disease,” “experiences and challenges of self-management of SCD,” “recommendations for self-management and transitional care,” and “perceptions of digital self-management program.” Subthemes for each of the major themes are summarized below and in Textbox 2; additional quotations illustrating the themes and subthemes can be found in Multimedia Appendix 1.

Impact of Sickle Cell Disease

Uncertainty of Sickle Cell Disease

Adolescents, parents, and HCPs all described the challenges of managing the uncertainty of SCD. Parents and HCPs described the uncertainty of complications such as strokes and downstream consequences associated with them such as cognitive and vision impairments. Adolescents worried about the uncertainty of vaso-occlusive crises and whether any feeling of pain would escalate into a crisis and whether it would affect school or activities with friends. HCPs described the emotional impact this had on adolescents, resulting in frustration and a feeling of loss of control over their lives.

Impact on Developing Peer Relationships

Adolescents reported frequently missing out on activities with friends, such as swimming and playing outside, along with school events due to appointments and crises and described feeling different from their peers. Adolescents reported that this affected their ability to create and maintain friendships, especially when they were younger. Adolescents and parents described experiences of being bullied for seeming different from their peers; however, some adolescents and parents found that as they grew older, it became easier to make friends who were considerate of their condition. Other adolescents preferred not to speak with friends or teachers about their disease and kept it to themselves. Parents and HCPs found that children would also forgo strategies to prevent a crisis around their friends because they wanted to fit in. HCPs discussed the challenges of managing SCD during adolescence when youth were going through many different transitions in their lives and were trying hard to fit in among their peers.

Academic Impact

Adolescents discussed missing many days of school, especially with crises and appointments, resulting in missed homework, lessons, tests, and projects and catching up with missed schoolwork. Keeping up with missed schoolwork was also a source of stress described by adolescents, parents, and HCPs. Adolescents described how keeping up with missed schoolwork was a source of stress that caused vaso-occlusive crises. All 3 groups noted that teachers needed education on the disease so that they would not be skeptical of adolescents’ symptoms or absences.

Sickle Cell Disease Is Stigmatizing

Adolescents described difficulties in explaining their disease to others and dealing with negative responses from others, which was echoed by HCPs. Negative responses from peers were often exacerbated by negative responses and misunderstanding of their condition among teachers. HCPs described the racial stigma of SCD among HCPs in emergency departments. Other HCPs described the disease-related stigma adolescents faced when they sought care, often being labeled as *drug-seekers*. HCPs also described the cultural stigma perceived to exist among some of the ethnic groups who typically inherited SCD.

Experience and Challenges of Self-Management

The Internet Is a Source of Sickle Cell Disease–Related Education

Adolescents learned about SCD from HCPs, parents, and frequently from the internet. However, using the internet to learn more did not always meet their needs in a developmentally appropriate way. Parents used the internet as a resource and informed their children about the disease. They knew which websites were more reputable and accurate than others to get their information.

Managing Emergency Department Visits

Adolescents and parents highlighted a need for further awareness and education among emergency department staff on SCD and its management. HCPs described the challenges adolescents would face in attending emergency departments that were not familiar with them or SCD; this often resulted in delays in pain management. Adolescents and parents found that they waited too long for pain management at certain emergency departments and thus preferred visiting hospitals where emergency departments had implemented an SCD protocol or who had experience managing SCD vaso-occlusive crises.

Self-Management Is a Joint Effort

Adolescents believed managing their disease was primarily their responsibility along with their parents, HCPs, and sometimes friends, and adolescents described it as a joint effort between everyone. They knew as they grew older, self-management was ultimately their own responsibility, but their parents were still involved in reminding them to take their medication, make appointments, bring them to appointments, knowing when to go to the hospital, and to advocate for them when needed.

Adolescents said that they were starting to take their own medication and taking preventative measures against crises. Having supportive friends and family, communicating with friends with SCD, and taking charge of their disease were all strategies in their self-management. Parents said that they were still mostly managing their teen's disease but that they were trying to step back and give adolescents opportunities to take charge of their care.

Lack of System Level Supports

Parents described the financial challenges of managing SCD. They took time off from work for hospital visits and emergency department admissions and felt worried when they had to go to work while their child was still in the hospital. HCPs discussed the lack of dedicated financial and practical supports for SCD in the province. Another challenge to accessing existing supports was the lack of awareness among families, often due to financial and communication barriers due to a largely immigrant population.

Table 1. Demographic characteristics of adolescents.

Characteristic	Adolescents (N=19)[a]
Age in years, mean (SD)	15 (1.9)
Sex, n (%)	
Female	12 (66)
Male	6 (33)
School grade, n (%)	
Grade 7	1 (12)
Grade 8	6 (33)
Grade 9	2 (11)
Grade 10	1 (12)
Grade 11	5 (27)
Grade 12	2 (11)
Other	1 (12)
Diagnosis[b], n (%)	
Sickle cell disease hemoglobin SS	14 (77)
Sickle cell disease hemoglobin SC	3 (16)
In the past 6 months, how many times have you..., mean (SD)	
Been admitted to the hospital[c]	2 (2.6)
Been to an emergency department	1.05 (1.8)
Current prescribed medications for sickle cell disease management[d], n (%)	
Acetaminophen	1 (5)
Morphine	3 (16)
Folic acid	5 (27)
Hydroxyurea	5 (27)
Penicillin	1 (5)
Deferasirox	8 (44)
Calcium	1 (5)
Aspirin	4 (22)
Salbutamol	1 (5)
Fluticasone	1 (5)

[a] One participant did not respond to the entire questionnaire.

[b] N=2 did not respond; participants could list more than 1 diagnosis.

[c] N=1 did not respond.

[d] N=1 did not respond; participants could list more than 1 medication.

Table 2. Computer use of adolescents.

Characteristic	Adolescents (N=18)[a]
Do you use a computer at home?, n (%)	
Yes	17 (94)
No	1 (5)
In 1 week, how many hours do you use the computer?, n (%)	
Not at all	0 (0)
<1 hour	1 (5)
1-2 hours	2 (11)
2-3 hours	0 (0)
3-4 hours	4 (22)
4-5 hours	1 (5)
5-6 hours	3 (16)
6-7 hours	3 (16)
>7 hours	4 (22)
Please circle the number that goes with how comfortable you feel using a computer, n (%)	
Not at all comfortable	0 (0)
A little comfortable	0 (0)
Comfortable	9 (50)
Very comfortable	9 (50)

[a] One participant did not respond to the questionnaire.

Table 3. Demographic characteristics of health care providers.

Characteristic	Health care providers (N=17)
Age in years, mean (SD)	38.6 (7.2)
Sex, n (%)	
Female	14 (82)
Male	3 (17)
Profession, n (%)	
Staff hematologist/oncologist	1 (5)
Fellow	2 (11)
Resident	3 (17)
Staff nurse	4 (23)
Advanced practice nurse	3 (17)
Psychologist	2 (11)
Other	4 (23)
Number of years of health professional experience (including training), mean (SD)	17.6 (8.4)
Number of years of pediatric hematology/oncology experience, mean (SD)	8 (7.9)
Are you a parent?, n (%)	
Yes	6 (35)
No	11 (64)

Textbox 2. Summary of themes and subthemes.

Self-management and transitional care needs of adolescents with sickle cell disease (SCD)

1. Impact of SCD
   - Uncertainty of SCD
   - Impact on developing peer relationships
   - Academic impact
   - SCD is stigmatizing
2. Experiences and challenges of self-management
   - The internet is a source of SCD-related education
   - Managing emergency department visits
   - Self-management is a joint effort
   - Lack of system-level supports
3. Recommendations for self-management and transitional care
   - Information to cope with and live with SCD
   - Self-advocacy and communication
   - Social support
   - Information for future planning
   - Transition is not one-size fits all
4. Perceptions about digital self-management program
   - Facilitating transition care
   - Accessibility
   - Effectively engaging adolescents and families

Recommendations for Self-Management and Transitional Care

Information to Cope With and Live With Sickle Cell Disease

All groups voiced that understanding information about SCD was at the core of self-management. Adolescents wanted to know how they got the disease, symptoms, diagnosis, treatment options, different types of the disease, genetic components, and strategies for preventing vaso-occlusive crises. Adolescents were interested in knowing more about their limits to physical activity and how they could make the most of being involved in activities without triggering a crisis. They discussed the importance of understanding the steps to take during a crisis and how to manage it in terms of medication and care. Parents and HCPs believed adolescents needed to understand the consequences of nonadherence to medication. HCPs suggested that empowering adolescents with strategies for preventing crises could help them cope with the uncertainty of SCD.

Self-Advocacy and Communication

Adolescents found that explaining SCD to teachers and peers was difficult because they did not know the best way to describe the disease or answer their questions. In addition, HCPs and adolescents cited a need for learning strategies to communicate about their disease to peers, teachers, professors, and future employers as part of their self-management. HCPs believed adolescents should learn to advocate for themselves to ensure they could succeed at school while ensuring the stress and schedule did not lead to a crisis. HCPs and parents emphasized that adolescents should know specific information and terms to use when going to the emergency department to effectively advocate for themselves and expedite their care, especially to HCPs who may be less knowledgeable about SCD.

Social Support

All 3 groups discussed the importance of social support and speaking to other adolescents with SCD. Adolescents found social support from their peers with SCD was beneficial in allowing them to talk about their experience with others who had similar experiences. Parents and adolescents described the benefits of a camp for kids with SCD and having a positive experience in terms of friendships and improvements in confidence. All groups mentioned the need for motivating role models who had SCD and had achieved success in some form. Adolescents and HCPs also believed older adolescents with SCD mentoring younger children would be helpful in terms of both social support and the transition process.

Information for Future Planning

All participants discussed the different impacts of SCD on future planning, and they recommended that challenging topics should be discussed early on so that adolescents could be given strategies to manage these issues. Adolescents mainly discussed the impact of SCD in choosing postsecondary education or training. Adolescents emphasized wanting to balance their ambitions with the realistic expectations of their disease as they grew older. Adolescents as well as HCPs described a need to inform adolescents about the genetics of the disease to ensure they understood the impact it could have on their future relationships and planning for children. HCPs believed this factor was important, especially given the lack of discussion about the disease among families. HCPs and parents believed education regarding risk-taking behaviors such as alcohol, drugs, and sex and its effects on SCD was important for adolescents to learn about. Parents were concerned about the adverse effects drugs could have with their disease and highlighting the importance of that to their children.

Transition Is Not One-Size Fits All

Adolescents’ thoughts on the transition to adult health services depended on their disease severity. Some adolescents felt less worried because they rarely had crises. Patients, parents, and HCPs were in agreement that the ideal time for transition would depend on the individual’s disease severity and cognitive abilities. Adolescents expressed interest in being taught how to manage their condition on their own such as making their own appointments and going to them alone. All participants emphasized that transition should be a gradual process.

Perceptions About Digital Self-Management Program

Adolescents, parents, and HCPs felt that a digital self-management program could be very useful, and they were unanimous in their suggestions on features for a digital self-management tool. Their recommendations for informational topics and features to include are summarized in Table 4.

Facilitating Transition Care

Adolescents and parents believed a digital self-management tool would be useful for transitioning to adult care as it could be used both independently and with families. Parents discussed the benefit of a website in cultivating independence in the adolescents because it could be a self-directed activity. All groups also described the benefits of a reliable resource that could be privately accessed by teens to learn about sensitive topics, as they may feel less comfortable speaking to HCPs and parents about those topics. HCPs believed such a program could be a medium to share these resources with families in an accessible way and provide educational resources for parents to foster self-management behaviors among their adolescents.

Table 4. Essential components of a digital sickle cell disease self-management program.

Format	Web-based or mobile app
Educational content to include	
Medication	Dosages; mechanism of action; side effects; consequences of nonadherence; alternative options for treatment; interactions with drugs, alcohol, and other risk-taking behaviors; cost of medication and coverage by insurance; addiction, tolerance, appropriate use; and safe-keeping medications
Information about SCD[a]	What is SCD?; genetics of SCD; what happens during a vaso-occlusive crises crisis?; symptoms and types of SCD (eg, milder types, pica, priapism, enuresis); treatment options; complications of SCD; latest research and developments in SCD; and information on risk-taking behaviors
Preventing crises and pain management	Strategies to prevent vaso-occlusive crises (eg, keeping hydrated, limits to physical exertion, dressing in layers); how to manage stress in school?; what to do when a crisis comes on; how to make the most of being involved in school and activities without triggering a crisis; multimodal *3P* approach to pain management (psychological, physical, pharmacological); at what point should I come to the hospital if I have a crisis?; and advocating for appropriate treatment at hospitals
Resources	Information about SCD organizations; social and financial supports available for SCD; available SCD-related education to families; and insurance information
Communication	Self-advocacy; keeping up with schoolwork; communicating with peers about SCD; communicating with teachers, professors, and employers about SCD; and communicating with HCP[b] about SCD
Future	Guidance on pursuing successfully postsecondary education and careers; implications for relationships with others with sickle cell trait; and risk-taking behaviors and SCD such as drugs, alcohol, and sex
Desired characteristics and features	
Cultural appropriateness	Addressing misconceptions about SCD; plain language for immigrant populations; and communicating with extended family and community members about SCD
Social support	Forum or chat option to communicate with other youth with SCD; peer mentorship from older adolescents with SCD; and examples of role models
Ask an HCP questions	Forum to ask questions; submit a question to be answered by an HCP; and live chat with an HCP
Interactive and multimedia	Videos of youth explaining their experiences with SCD; visuals and diagrams; and games
Safety and trustworthiness	Username and password-protected use; monitored social features; and evidence-based medical and practical information

[a] SCD: sickle cell disease.

[b] HCP: health care provider.

Accessibility

HCPs and parents both liked the accessibility of a digital self-management program, given the availability of the internet; adolescents and HCPs believed a website or mobile phone app were potential platforms. One parent described the accessibility a digital program could provide, especially for those with limited financial resources and time to attend in-person education sessions.

Effectively Engaging Adolescents and Families

Adolescents, parents, and HCPs all believed the digital self-management program needed to effectively engage youth and their families. Adolescents were less likely to use it if it was less engaging or too difficult to understand. All groups were in strong agreement about the need for a chat room or social support feature for adolescents to connect with peers with SCD to share their experiences and ideas and have emotional support from others going through similar experiences. Parents and adolescents had a concern about the safety of a digital program and ensuring any social features had a way to safeguard that only the intended users were accessing the program and ensuring the privacy of adolescents. Finally, participants described the benefit of a program helping to reduce the stigma associated with the disease by educating the public about the disease and preventing misconceptions about the disease.

Discussion

Principal Findings

To the best of our knowledge, this is the first study that examines the recommendations for a digital self-management and transitional care program for adolescents with SCD from the perspectives of adolescents, parents, and HCPs and re-examines the impact of SCD on adolescents. Participants described the psychosocial impacts of SCD and provided recommendations for self-management and transitional care to address these concerns. Adolescents, parents, and HCPs endorsed a digital platform as an effective and accessible way to deliver this information and provided recommendations for tailoring the program to adolescents with SCD. Adolescents focused on self-management experiences, especially those pertaining to school, friendships, and postsecondary education choices, whereas parents and HCPs focused on transitional care issues and sensitive topics.

Adolescents in this study described many of the psychosocial impacts of their disease, which pose challenges in disease self-management and transition to adult health care for this population. These findings support what has previously been described in studies with adolescents and adults with SCD. These include difficulties in developing peer relationships; limitations in physical activity; school and activity absenteeism; feelings of worry and uncertainty; disease-related stigma; and negative responses from peers, teachers, and HCPs [3,4,25-32]. These challenges were described by participants in the context of Ontario, Canada, and highlight the continued perceived challenges this population faces throughout childhood and adolescence. All participants highlighted the need for increased awareness of SCD among HCPs and school teachers, appropriate support for youth to succeed academically, and support to reduce the burden of the disease on families. Participants discussed the stigmatization of the SCD and several unique issues for the Canadian context. HCPs highlighted the SCD-related stigma among adolescents' ethnic communities. Previous studies with families of children with SCD in African settings found varying levels of stigma toward SCD [33-36]. For families who immigrate to Canada from these nations or have ancestry from these nations, negative beliefs toward SCD may linger. To address these issues, participants in our study highlighted that awareness and communication were critical in addressing these impacts and could be delivered through a digital tool. Moreover, HCPs and parents in our study discussed a perceived lack of financial and practical supports and resources for SCD in Ontario, Canada. These findings appear to be reflected in a study examining the quality of information on SCD on the internet where none of the top 12 websites examined were of Canadian origin [37].

Adolescents, parents, and HCPs focused on empowerment through education and understanding SCD for self-management. The importance that adolescents placed on medical information is consistent with the qualitative study with youth with SCD and thalassemia by Atkin et al, which suggests that information is a resource that could offer a sense of control over adolescents' lives, allowing them to develop preventative strategies and appropriate courses of action in response to crises [26]. This study extends those findings by identifying and articulating the specific topics of SCD information and self-management strategies needed for a digital self-management program.

Developing self-advocacy skills and communication strategies for communicating with peers, teachers, employers, and HCPs were highly emphasized by all groups as important in successful self-management and transition to adult health care. Similar emphasis on these skills has also been described by adults with SCD who shared their experiences in managing SCD in a qualitative study by Tanabe et al. Adults in that study highlighted that they often had to be their own advocates and make things work for themselves even with the limitations of the disease [38]. These recommendations are also in accordance with evidence showing that self-presentation and communication of condition to HCPs reduces stigmatization and allows for better care [28,39].

Adolescents in this study described self-management as a joint effort from everyone in their life; they sought support from friends, their families, and HCPs. They also described a need for social support from role models and peers with SCD. All groups discussed the importance of social support for dealing with negative emotions, feeling understood, and learning self-management strategies. Social support and role models as psychosocial interventions for SCD have been previously investigated as potentially effective interventions for adolescents with SCD [40-43]. These findings were consistent with views expressed by young adults in a qualitative study by Sobota et al examining the transitional care needs of young adults with SCD. Young adults in that study found that hearing about the transition process from someone who had already gone through it was more compelling [44]. Adolescents in this study believed a digital self-management program was an effective way for friends, peers, and families to learn about SCD and for them to connect with other youth with SCD.

All participants in this study preferred to learn about challenges and considerations they would face in the future regarding postsecondary education, choosing a career, and risk-taking behaviors (eg, drugs, sex) early on. Parents and HCPs believed information on risk-taking behaviors provided on a digital medium would make it easier for adolescents to access this information. Previous studies among youth with chronic diseases such as chronic pain or juvenile idiopathic arthritis identified similar information needs among adolescents and young adults [45,46]. This finding is also consistent with previous studies of adolescents’ preference for learning about health information on the Web, especially those regarding sensitive topics due to the anonymity offered by the internet [47,48]. All groups of participants in this study recommended a transitional care process beginning early in adolescence and tailored to the spectrum of SCD severity. They emphasized a need for a gradual process that allowed adolescents to take responsibility for specific tasks in their health care. These findings are well aligned with the findings of a systematic review of transition from adolescent to adult care for SCD, which recommended that transition programs be patient centric and flexible, and allow adolescents to explore independence and develop skills for managing SCD [49].

Development of a digital self-management and transitional care program tailored for adolescents with SCD was well endorsed by all participants. Parents, adolescents, and HCPs highlighted the accessibility of a digital program for families. HCPs believed that a potential mobile or Web-based program could be an acceptable format to be used by families and could help to address some of the stigmas among communities regarding the disease. Our findings are similar to those of a survey-based study conducted by Badawy et al regarding the mobile phone app preferences for medication adherence among adolescents with SCD. Our study extends the findings of Badawy et al by clearly describing in detail the important education topics to cover and the format in which youth preferred to receive social support in a comprehensive digital self-management program and the benefits they perceived [50]. Our study exemplifies the first step in effectively engaging patient and family users of digital interventions for chronic conditions by conducting a thorough investigation of their needs to understand their intended use and goal for these populations [51]. A systematic review of adolescents’ use of mobile phone and tablet apps for management of chronic conditions identified 3 of 4 studies that involved patient input in the development of the app [52]. However, only 1 of the 3 studies conducted an in-depth qualitative examination of the requirements articulated by patients and involved parents in the development process [52,53]. An earlier systematic review of the effectiveness of internet self-management interventions on health outcomes in adolescents with chronic conditions had similar findings, where interventions demonstrated limited involvement of parents [54]. Majeed-Ariss et al suggested that future interventions take into account social and family processes in their delivery and harness opportunities to promote shared self-management skills and knowledge [52].

Limitations

The limitations of this study included the sample of participants who were recruited from a single tertiary care pediatric center and therefore limits generalizability of the findings. Individuals willing to participate in the interviews may be more motivated to manage their condition or have a more serious disease; this may limit the transferability of the results. This study was initially conducted in 2012; thus, perceptions and ideas about a potential digital self-management program may differ from the current time (eg, changes in delivery platform preferences). However, the focus of this study was on experiences and challenges related to adolescents managing SCD and the way in which a hypothetical digital program could assist in this self-management. Thus, any potential digital self-management program for adolescents with SCD should adhere to contemporary norms in the platform and interface design while being informed by the core components described by participants in this study. Furthermore, adolescent and parent participants were not offered an interviewer of the same sex or race as them, which may have prevented them from discussing more sensitive topics or speaking frankly with the interviewer. Atkin et al found that the sex of the interviewer may have been particularly important for adolescents while their previous work with parents of children with hemoglobinopathies found that race and sex were important characteristics of interviewers [26,55]. Finally, due to availability and timeline of the study, only a small sample of parents was included, with no male caregivers included, limiting the transferability of parents’ perspectives to other parents or caregivers.

In conclusion, participants in this study described the continued challenges youth with SCD face in Ontario, Canada, and provided recommendations for addressing these. Participants found value in developing a digital self-management program to address some of these challenges. Their perspectives on challenges and recommendations for self-management and transitional care will ensure the development of an acceptable and relevant digital program that meets the current needs of adolescents. Adolescents with SCD recommend the creation of a digital self-management program that provides in-depth SCD-related education in an accessible manner; fosters self-advocacy and communications strategies to be used in school, the workplace, and in health care settings; allows for social support; and provides an avenue to address challenging topics. This is the first study to identify the essential components of a digital self-management and transitional care program for this population and identify these requirements in relation to the psychosocial challenges that they face.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Themes and subthemes with exemplar quotations from participants.
[PDF File (Adobe PDF File), 54KB - pediatrics_v1i2e11058_app1.pdf]

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Abbreviations

CBT: cognitive behavioral therapy
HCP: health care provider
SCD: sickle cell disease

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Review

Electronic Mentoring Programs and Interventions for Children and Youth With Disabilities: Systematic Review

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Abstract

Background: Children and youth with disabilities experience many challenges in their development, including higher risk of poor self-esteem, fewer friendships, and social isolation. Electronic mentoring is a potentially viable approach for youth with disabilities to access social and peer support within a format that reduces physical barriers to accessing mentors.

Objective: Our objective was to synthesize and review the literature on the impact of electronic mentoring for children and youth with disabilities.

Methods: We conducted a systematic review, completing comprehensive searches of 7 databases from 1993 to May 2018. We selected articles for inclusion that were peer-reviewed publications, had a sample of children or youth with disabilities (≤25 years of age), and had empirical findings with at least one outcome focusing on the impact of electronic mentoring. Two reviewers independently applied the inclusion criteria, extracted the data, and rated the study quality before discussing the findings.

Results: In the 25 studies meeting our inclusion criteria, 897 participants (aged 12-26, mean 17.4 years) were represented across 6 countries. Although the outcomes varied across the studies, of 11 studies testing significance, 9 (81%) reported a significant improvement in at least one of the following: career decision making, self-determination, self-advocacy, self-confidence, self-management, social skills, attitude toward disability, and coping with daily life. The electronic mentoring interventions varied in their delivery format and involved 1 or more of the following: interactive websites, virtual environment, email, mobile apps, Skype video calls, and phone calls. A total of 13 studies involved one-to-one mentoring, 6 had group-based mentoring, and 6 had a combination of both.

Conclusions: The evidence in this review suggests it is possible that electronic mentoring is effective for children and youth with disabilities. More rigorously designed studies are needed to understand the impact and effective components of electronic mentoring interventions.

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KEYWORDS

youth; disability; eHealth; mentoring; review; peer support; adolescent; child; disabled children; disabled persons; telemedicine

Introduction

Background

Approximately 3.7% of Canadian children [1] and 5.6% of American children [2] have a disability and encounter many challenges to their full participation and inclusion in society. They are frequently socially isolated, physically excluded, and at risk of abuse and poor developmental, social, and vocational outcomes [3,4]. Further, they are often less well equipped with emotional, social, and cognitive resources to achieve positive life outcomes [3,5]. Youth with disabilities are underrepresented in higher education and have a lower likelihood of completing school than do youth without disabilities [6,7]. These trends are often a result of negative attitudes, discrimination, inaccessible environments, and lack of resources and social supports [8-10]. Focusing on children and youth with disabilities is critical because disadvantages are compounded for those who start life with a disability [11,12]. They are a unique population that often encounters multiple disadvantages, particularly with developmental tasks, social development, and role functioning [13,14].

Mentoring is a promising mechanism that could help to enhance youth's inclusion in society [15-18], while offering support and coping strategies [19]. Mentoring involves a relationship between a more experienced individual, who serves as a role model and shares his or her experiences, and a less experienced individual [17,20,21]. Mentoring can offer informational, practical, and emotional assistance along with coping skills [16,22-24]. Until recently, most mentoring programs have not included or specifically targeted youth with disabilities [16,25]. Having mentors for youth with disabilities is critical for developing their social capital, self-determination, quality of life, and career development goals [16,17,26-29]. Research focusing on face-to-face mentoring for youth with disabilities shows beneficial impacts on transition to postsecondary education and employment [16,26], social competence and self-esteem [30], and independent living skills [11].

While there are benefits to face-to-face mentoring for improving transitions to school or employment for youth with disabilities, there are challenges associated with this type of mentorship, including difficulty in finding and accessing mentors [16]. Electronic mentoring (e-mentoring), defined as a "computer mediated, mutually beneficial relationship between a mentor and a protégé which provides learning, advising, encouraging, promoting and modeling that is often boundaryless, egalitarian and qualitatively different than traditional face-to-face mentoring" [31], can help to overcome some of these challenges. Computer-mediated communication has helped to advance e-mentoring as a promising mode of developing mentoring relationships and changing the conditions under which mentoring is sought and offered [31]. Another potential advantage of e-mentoring is that it offers a viable platform for increasing the availability and accessibility of mentors [32].

Consistent evidence shows that Web-based platforms and mobile apps can influence learning and behavior change [12,33-39]. Given that technology is already an important component of adolescents' social networks, whereby most youth seek information and communicate over the internet and approximately 88% of American teenagers have a mobile phone [40], e-mentoring interventions are a promising approach to helping youth with disabilities. This mode of mentoring has the potential to enhance social support while reducing barriers because of differences in sex, ethnicity, disability, or geographic location [14,41,42]. People with mobility issues or speech, hearing, or vision difficulties can participate when using appropriate adaptive devices [43].

There are barriers associated with traditional, face-to-face mentoring, limiting the full participation of certain groups, including youth with disabilities. The Web-based, electronic delivery format offered by e-mentoring can help to make mentoring relationships more accessible and available to groups that have had limited access to mentoring [31]. Electronic communication allows for flexibility in matching partners and asynchronous communication [44]. Research shows that e-mentoring has many of the same benefits as face-to-face mentoring, including informational, psychosocial, and instrumental benefits [45]. Among youth without disabilities, Web-based support has been shown to predict a lower incidence of depressive thoughts and can buffer the effects of peer victimization [46].

Challenges associated with the implementation of e-mentoring programs include access to technology, computer literacy, and adequate communication skills [16,31,47]. Further, finding the right mentors, developing a rapport, and keeping participants engaged can be difficult, especially if they have never met face-to-face [44,48]. Miscommunications can also occur because Web-based interactions conceal social cues and inhibit communication [31,49].

Objectives

E-mentoring provides an opportunity to "level the playing-field...for those who otherwise would be left out of important informal networks" [45], including youth with disabilities. Although there has been an increase in e-mentoring research for youth with disabilities, this work has not yet been synthesized. This systematic review of e-mentoring research is an important step in identifying the common components of e-mentoring interventions and developing an understanding of the effectiveness of this approach for youth with disabilities. Our specific objectives were to (1) critically appraise and synthesize the peer-reviewed evidence on e-mentoring for children and youth with disabilities, and (2) highlight gaps in understanding and areas for future research.

Methods

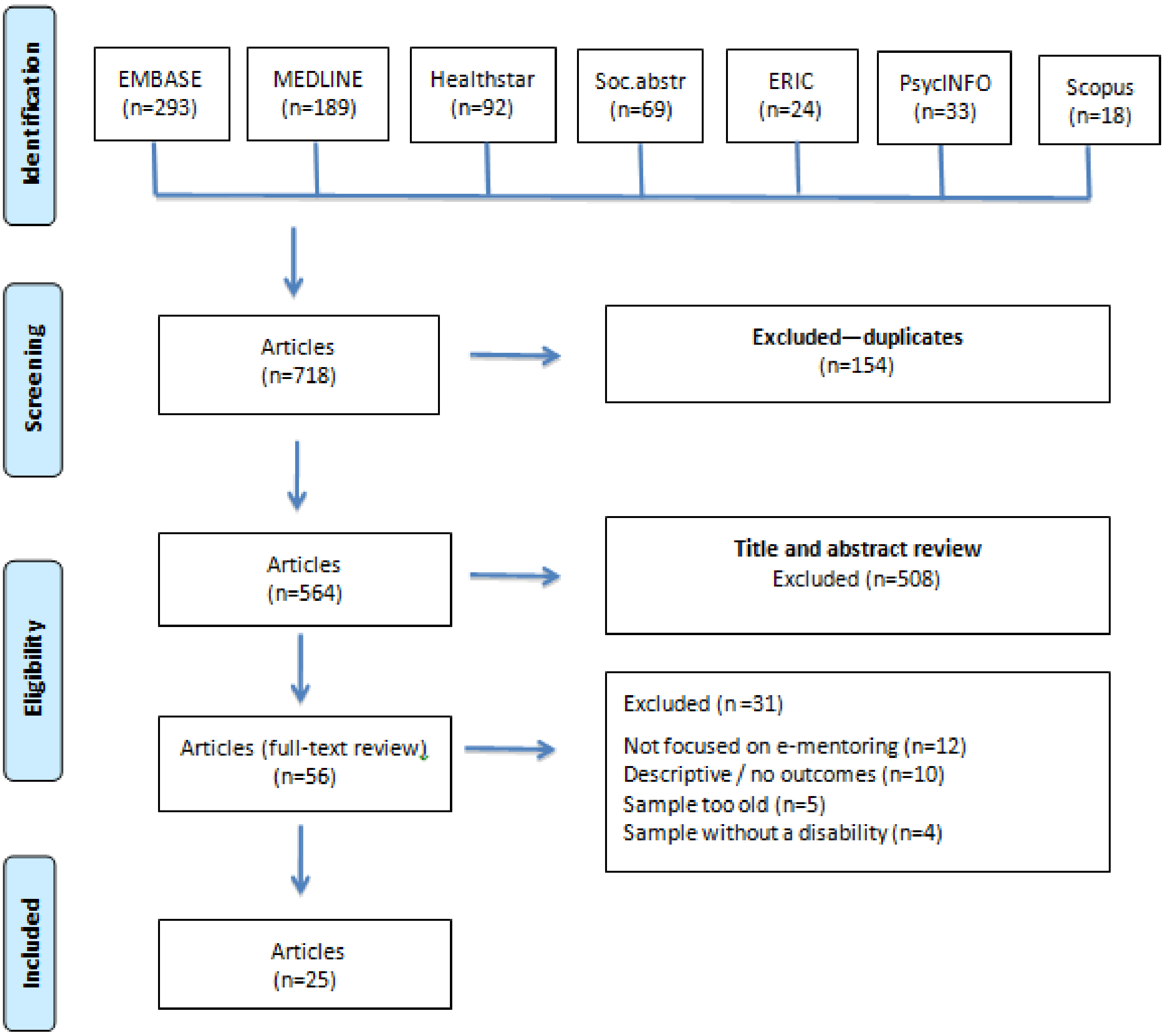
Rationale for a Systematic Review

We conducted a systematic review because a meta-analysis was not feasible given the heterogeneity of the studies reviewed (eg, various disability types, study populations, interventions, and outcome measures). Systematic reviews are the next highest level of evidence aiming to critically appraise the evidence of e-mentoring for children with disabilities and provide an unbiased summary of current practices [50].

Search Strategy and Data Sources

We conducted a comprehensive search of the published peer-reviewed literature using the following databases: MEDLINE, EMBASE, Healthstar, Sociological Abstracts, Education Resources Information Center (ERIC), PsycINFO, and Scopus (see Figure 1). We searched for headings and key terms related to mentoring, electronic and computer-mediated forms of mentoring, disability, and youth (see Multimedia Appendix 1 for full list of terms). We searched for articles published between 1993 and May 2018. We also manually searched the reference lists of all articles meeting our inclusion criteria.

Figure 1. Search process flow diagram. ERIC: Education Resources Information Center; Soc.abstr: Sociological Abstracts.



Article Selection

To select articles for the review, we applied the following inclusion and exclusion criteria. Eligibility criteria were (1) publication in a peer-reviewed journal between 1993 and May 2018, (2) study population focusing on children or youth (aged ≤25 years) with a disability (eg, physical, developmental, intellectual, or sensory), and (3) focus on e-mentoring (defined as computer-mediated technology, such as the internet, mobile apps, or Skype). We excluded articles that (1) were not peer reviewed (eg, opinion, editorial, gray literature, or reports) and (2) focused on descriptions of e-mentoring programs that did not have empirical findings.

Our initial search identified 718 articles for potential inclusion in this review (see Figure 1). After removing the duplicates, 2 authors independently reviewed the titles and abstracts for inclusion. A total of 508 abstracts did not meet our inclusion criteria. We read the remaining 56 articles and independently applied the inclusion criteria. Of these, 25 articles met our inclusion criteria. We kept field notes of our inclusion and exclusion decisions and discussed among the team any discrepancies on which articles were to be included.

Data Abstraction and Synthesis

The first author (SL) extracted and compiled the data from the 25 articles selected for review using a structured abstraction form. She abstracted relevant information on each study (eg, year, country, objectives, disability type, study design, intervention, key findings, quality appraisal score, and limitations; see Multimedia Appendix 2). All 3 authors reviewed all 25 articles and abstracted data for accuracy. We noted the limitations and risk of bias for each study.

We synthesized our findings based on the guidelines for narrative synthesis [51], which is relevant for reviews with diverse methodologies. Our method of synthesis involved a structured examination and summary of all studies included in the review. Our first step organized the studies into categories to help guide the analysis. Next, we explored within-study findings through a narrative description of each study's results while considering the quality and rigor of the design. Our next step involved undertaking a cross-study synthesis while considering variations in study participants and design [51].

Methodological Quality Assessment

Our findings and recommendations for future research are based on the overall strength and quality of the evidence we reviewed. The measure of bias and quality assessments were based on the American Academy of Neurology' guidelines [52] to assess interventions and randomized controlled trials (RCTs), and Kmet and colleagues' [53] standard quality assessment and risk of bias (for all other quantitative and qualitative studies). The American Academy of Neurology guidelines are a widely recognized tool for therapeutic interventions to help inform appropriate recommendations for interventions [52]. All 3 authors independently reviewed each article and assigned a score for each item and an overall score.

All 3 authors independently applied a 14-item checklist for quantitative studies and a 10-item checklist for qualitative studies [53] to help assess the quality of evidence for each study. Multimedia Appendix 3 and Multimedia Appendix 4 show the results of the quality assessments. We did not exclude any studies from our review based on quality. We followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses, a method of transparent reporting [54]. We noted any issues concerning study limitations or risk of bias. Any discrepancies in the ratings were resolved through discussion and reexamining the article.

Results

Study and Participant Characteristics

A total of 25 articles met our inclusion criteria for this systematic review (see Figure 1). Of these, 14 studies were conducted in the United States, 6 in Canada, 2 in the Netherlands, 1 in Australia, 1 in Israel, and 1 in South Korea. Reported sample sizes of the mentees ranged from 1 to 189, for a total of 897 mentee participants. Ages of the participants ranged from 12 to 26 years (mean 17.4 years). The types of disabilities these studies focused on were rheumatic disease, juvenile arthritis, cerebral palsy, spina bifida, muscular dystrophy, pediatric transplant, blindness or vision impairments, chronic pain, traumatic brain injury, and various other types (eg, vision, hearing, learning, or developmental disabilities).

Outcome Measures

Several standardized and nonstandardized measures were used to explore the role of e-mentoring for youth with disabilities. Studies that used standardized measures assessed the Dutch arthritis self-efficacy scale, self-management, self-determination, self-advocacy, career decision self-efficacy, mathematics self-advocacy, self-confidence, quality of life, the Miller Hope Scale, sense of community, self-perception profile, pain inventory, daily functioning, and children's inventory of social support. Nonstandardized measures assessed perceived usefulness, use, user acceptance, satisfaction, fidelity, engagement, feasibility, acceptability, medication use, adherence, social support, social behavior and functioning, loneliness, self-reported coping, pain, frequency of communication, employment, and program likes and dislikes.

Methodological Design and Theoretical Frameworks

The methodological designs varied across the studies and included 3 RCTs, 7 surveys, 1 case study, and 1 feasibility study. Of the 25 studies, 12 (48%) had a theoretical framework such as self-efficacy theory, social support theory, electronic socioemotional support theory, conceptual framework for peer mentoring support in health care, self-determination theory, social learning theory, symbolic interaction theory, and theory of change.

Intervention Components

Mode of Delivery

The e-mentoring interventions varied in their delivery format and involved 1 or more of the following: interactive websites [13,55-60], virtual environment [27,61-63], email [19,47,64-71], mobile apps [60,63,72], Skype video calls [60,73-75], and phone calls [68,71]. Overall, studies involving e-mentoring apps reported they were a feasible and helpful tool for facilitating students' understanding [60,72]. Studies including email-based mentorship programs reported improved mentor-mentee communication [64,65,70], particularly with respect to personal, more informal communication [19,47,70]. When compared with face-to-face mentoring, e-mentoring through interactive websites had similar outcomes for self-efficacy, quality of life, and self-management [55] and for dealing with daily life [57], but were reported to be feasible [57,60] and fun [13] while providing a safe environment for socialization [58]. Skype-based mentorship programs were feasible [73], provided flexibility [74], were informational, and provided appraisal and emotional support [75]. Studies described that e-mentoring through virtual environments facilitated improvements in self-determination and self-advocacy [27,62], engagement [61], and persistence [27,62,63].

Mentoring Format

A total of 13 studies involved one-to-one mentoring [27,47,57,60,65-68,71-76], 6 had group-based mentoring [13,55,57-59,61], and 6 had a combination of both one-to-one and group mentoring [56,62-64,69,70]. No clear pattern emerged regarding differential benefits for one-to-one versus group-based mentoring programs.

Types of Mentors

The types of mentors and the training they received varied across the studies. Interestingly, the definition of mentor was used broadly across studies, particularly in what was considered a "more experienced individual." In total, 12 studies involved a mentor who had a similar type of disability to the mentee [13,47,55,57,59,65,66,68,71,73,74,77], whereas 2 studies had mentors who were near-peers without disabilities [60,61]. Meanwhile, 7 had adult mentors without disabilities [27,62-64,67,69,70], including 3 studies that defined clinicians [56,58,76] and a writing coach [72] as mentors. Positive effects of e-mentoring were reported for all types of mentors but, given the heterogeneity of outcomes, it was not possible to compare the effectiveness of types of mentors across studies.

Intervention Dosage

Of the 25 studies, 10 (40%) provided sufficient information to calculate the intervention dosage. The overall duration and dosage of the interventions in our review ranged from 0.31 hours per week to 2 hours per week, occurring over a period of 4 to 24 weeks. Of the 25 studies, 11 (44%) did not provide information on the hourly dosage of the intervention; however, information on the length of exposure was provided. For these studies, exposure ranged from 2 months to 4 years. No clear pattern emerged regarding the length of the intervention, and both shorter and longer interventions reported positive results. For example, Stinson et al [74] reported a relatively short intervention (2.5-5 hours) that was engaging and led to increased self-management ability, while Stewart et al [59] conducted a longer intervention (25-37.5 hours) and reported decreased loneliness, increased acceptance, and greater self-confidence.

Effectiveness of the Interventions

Although the outcomes of the interventions varied across the studies, of 11 studies testing significance, 9 (81%) reported that mentoring helped improve outcomes. For example, the studies in our review found that mentoring significantly improved career decision making (large effect) [68], personal hope for the future [68], positive attitudes about disability (large effect) [68], coping with daily life [57], self-determination [62], self-advocacy [63,69], self-confidence [59], career decision self-efficacy [77], self-management skills [73,74], mathematics self-efficacy [62], social skills [69], social contact [59], loneliness (decrease) [59], social and behavioral functioning [60], and written communication [67]. It is important to note that 1 study found that mentoring made no significant difference in self-efficacy, quality of life, and self-management [55]. Other improvements (not reporting significance tests) included the following: transition toward using augmentative and alternative communication devices [65]; science, technology, and mathematics learning and emotional supports [27]; persistence in science, technology, and mathematics education [63]; understanding of changes needed for school work [72]; informational, appraisal, and emotional support [75]; and understanding of colleges, majors, and admissions [77].

Outcomes by Level of Evidence

Multimedia Appendix 5 provides an overview of the e-mentoring intervention outcomes by level of evidence, classifying the studies according to the American Academy of Neurology guidelines [52]. We classified 3 studies were classified as level 1 (ie, rigorous RCT), 1 of which involved an interactive, group-based self-management website [55] for youth aged 17 to 25 years with rheumatic disease. Mentors were peer leaders who had the same condition. This RCT found no significant differences in self-efficacy, quality of life, or self-management between experimental and control groups [55]. Meanwhile, 2 level 1 studies involved one-to-one Skype calls [73,74]. Ahola Kohut and colleagues' study involved youth aged 12 to 18 years with chronic pain and mentors with a similar condition [73]. They engaged in 10 one-to-one Skype video calls (using iPeer2Peer). Their RCT found that the intervention was feasible and acceptable, with significant improvements in self-management skills and coping [73]. Stinson et al [74] used 10 one-to-one Skype-based video calls (iPeer2Peer) for youth aged 12 to 18 years with juvenile arthritis involving mentors with a similar condition. Their RCT found significant improvements in perceived ability to manage arthritis compared with controls. Participants were satisfied with the intervention and stated that they would recommend it to peers.

Only 1 study in this review was a level 2 (ie, matched cohort study, or RCT in a representative sample lacking 1 criterion in level 1) [52]. This mixed-methods prospective cohort study involved an online mentor with group-based and one-to-one components for youth with various types of physical and developmental disabilities [56]. Their findings showed that the utility of the intervention was modest, and only 20 of 50 (40%) participants engaged in chats with the mentor [56]. It was interesting to note that their mentor was a clinician (ie, occupational therapist) and not a youth.

None of the studies was a level 3 (ie, all other controlled trials). Meanwhile, 21 studies in our review were a level 4 (ie, all other studies), which had a wide range of outcomes (see Multimedia Appendix 5). Of the level 4 studies, 8 used an email mentoring approach [47,64-69,78] among youth with blindness, learning and cognitive disabilities, and various other types of disabilities (vision, hearing, and learning). These studies reported improvements in the transition to using assistive devices [65], career decision self-efficacy [68], attitudes about disability [68], preparation for college and employment [69], and written communication [67].

A total of 5 level 4 studies [13,57-59,66] used an interactive, group-based website in their approach to mentoring youth with cerebral palsy, spina bifida, juvenile arthritis, muscular dystrophy, and other physical, behavioral, and intellectual disabilities. Of these, 3 reported that their intervention was feasible [13,57,66], helped participants to cope with daily life [57], provided a space for socialization [58], and decreased loneliness while increasing acceptance, confidence, and a sense of community [59].

Of the level 4 studies, 4 used a virtual-world approach [27,61-63] and involved youth with various types of disabilities (ie, learning, visual, and physical disabilities, autism, and transplant recipients). These studies reported that their intervention helped to improve engagement and psychoeducational goals [27]; enhanced science, technology, and mathematics learning and emotional supports [62]; and improved persistence in science, technology, and mathematics education and self-advocacy [27,63].

A mobile app was used in 2 level 4 studies for their mentoring approach for youth with cerebral palsy [72] and traumatic brain injury [60]. These interventions were feasible and acceptable to participants [60,72], helped youth to define and achieve goals [60], improved social and behavioral functioning [60], and improved understanding of school work [72].

One level 4 study used Skype video calls of 1 hour a week for 4 weeks for their mentoring intervention and involved youth with various disability types [60]. This intervention was reported to be feasible and acceptable to participants [60,73,74], and helped youth achieve goals.

Based on the evidence in this review and using the American Academy of Neurology guidelines [52], we found that e-mentoring interventions are possibly effective or useful for this population. This rating is based on the overall rigor of the studies and the strength of the evidence [52]. Among the reviewed studies, 8 reported on the feasibility and acceptability of the program, whereby participants found that the mentoring format was favorable [13,57,60,64,66,71,73,74]; 1 study found that the utility of their Web-based intervention was modest [56].

Moderating Factors

Sex of Participants

A total of 4 studies noted sex differences in their mentoring program. Specifically, Barnfather et al [13] found that female participants with cerebral palsy or spina bifida were significantly more likely than male participants to contribute to the online discussion. Burgstahler and Doyle [70] reported that male participants sought and provided information about technology and the internet, while female participants communicated more frequently and shared more personal information. Another study found the greatest improvements in a science, technology, and mathematics e-mentoring program among female participants [27]. In Parkyn and Coveney's [58] e-mentoring program among youth with muscular dystrophy, they found that the intervention had a strong collective identity reflecting ideals of masculinity.

Communication and Relationship Development

One study exploring peer-to-peer and mentor-protégé relationships found that, although they performed similar functions, peer-to-peer relationships were more personal [64]. Burgstahler and Cronhiem [64] reported that barriers to an e-mentoring format included difficulty expressing feelings, dealing with lots of messages, and technical difficulties (eg, losing an internet connection or the website not working properly).

Another moderating factor reported by Cantrell et al [61] is the ability of the mentors themselves to develop relationships with participants and keep them engaged. Cohen and Light [65] similarly discovered that the frequency and length of communications between mentors and mentees may have been influenced by the availability of mentors and the quality of the match. Another study found that successful mentoring included an informal and supportive style, whereas unsuccessful mentoring was linked with a formal style [47]. Other moderating factors influencing the utility of the mentoring program included typing speed, cognitive skills, and need for support [13].

The results from qualitative studies highlight the perceptions and feelings of participants toward e-mentoring and the aspects they found successful, and the themes of discussion within mentoring sessions. E-mentoring was found to be a favorable environment [64] and a safe opportunity for socialization [58]. Barriers to successful mentoring included difficulty expressing feelings, lots of messages, technical difficulties, and a more formal communication style with a distant tone [47,64]. Themes in online mentored discussions included illness impact, self-management, non-illness–related goals, hobbies and social environments, bullying, physical appearance, school, and pain management [61,75]. Overall, the qualitative findings suggest that e-mentoring is an effective method for reducing the barriers associated with face-to-face mentoring [19,62,64,65,72] and facilitating the mentor-mentee relationship, particularly through informal communication [47,64].

Quality Assessment and Risk of Bias Within Studies

Two authors (SL, KK) independently rated the quality of each study using American Academy of Neurology guidelines (for levels 1-2) and Kmet and colleagues' [53] standard quality assessment (for all level 4 studies). Total scores for the quantitative studies range from 33% to 96% (mean 69.8%; Multimedia Appendix 3) and 35% to 85% for the qualitative studies (mean 72.2%; Multimedia Appendix 4). It is important to note that the quality assessments measure different items based on the qualitative or quantitative nature of the study. Most discrepancies reflected the extent of the applicability of each of the items. These articles were read and scored again by a third author (EC) and discussed until consensus was reached.

We carefully examined the limitations, quality, and risk of bias within each study. Areas of the quality assessment where quantitative studies scored lower included controlling for confounding and reporting estimates of variance. For most of the quantitative studies, random allocation and blinding of investigators and participants was not possible. For the qualitative studies, areas of the quality assessment scoring lower included the description of the sampling strategy and reflexivity of the account.

Risk of Bias Across Studies

We considered the risk of bias across the studies in our review. First, the studies were done in 6 countries, all which have varying programs and policies related to mentoring. Second, we included various types of disabilities and a wide age span and, therefore, caution should be used in generalizing the findings. Third, many of the studies had different interventions (eg, email, Skype, interactive website) and components (eg, length of program, type of mentor, one-to-one or group based), and it is unclear which components contributed to what outcomes. Fourth, although we consulted a librarian to help design our search strategy, it is possible we may have missed some articles. Fifth, various unstandardized measures were used, which limited our ability to compare across interventions.

Discussion

Principal Findings

This review explored e-mentoring interventions for children and youth with disabilities over a 25-year period. Although the outcomes varied across the studies, of 11 studies testing significance, 9 (81%) reported a significant improvement in at least one of the following: career decision making, self-determination, self-advocacy, self-confidence, self-management, social skills, attitude toward disability, and coping with daily life. Exploring this topic is important because youth with disabilities are at a higher risk of social isolation, discrimination, peer victimization, and poorer academic, social, and vocational outcomes than are youth without disabilities [4,8,9]. E-mentoring is a potentially viable approach offering a form of social support while overcoming challenges in accessing mentors in a face-to-face format [14].

Based on our assessment of the overall rigor of these studies and the strength of the evidence, we find that e-mentoring interventions are a possibly effective tool for youth with disabilities. These results are important because research shows that youth with disabilities encounter perpetual barriers and discrimination in participating in everyday activities [8,9]. Helping youth to develop their self-determination and self-advocacy skills is important because it is critical for optimizing an individual's participation and inclusion in society [79-81].

Program Design Implications

Our review highlights that several different types of e-mentoring interventions have the potential to positively influence youth with disabilities. Common components of programs showing improved outcomes included interactive website, Skype calls, virtual world, email, and mobile apps. These findings corroborate studies of programs for youth without disabilities reporting advantages to e-mentoring programs, including a range of delivery formats, such as email, face-to-face meetings, telephone calls, and video conferencing [45]. The benefits of e-mentoring programs for youth without disabilities are similar to those reported here and include informational, psychosocial (eg, improved self-esteem, increased confidence, and greater support for risk taking), and instrumental benefits for creating opportunities for the mentee [45]. These benefits are mirrored in our findings for youth with disabilities, where studies reported increased self-determination, self-advocacy, and self-confidence associated with e-mentoring programs. In our review, additional social benefits of e-mentorship included decreased loneliness, improved social skills, and increased social contact, supporting career decision making and improving positive attitudes toward their disability. The additional advantages of e-mentoring for youth with disabilities further the utility of this format for reducing the barriers associated with face-to-face mentoring and increasing the availability and accessibility of mentoring relationships.

Research Implications

Although the majority of the studies in our review had diverse samples, most did not explore any differences in outcomes based on sociodemographic characteristics of the participants, especially disability type. Many studies included participants with multiple disability types, and in these cases, differences in the effect of the intervention between disability types were not examined. It is possible that e-mentoring interventions provide differential benefits based on the specific needs of a given disability type; however, this was often not explored. Additionally, there was surprisingly little discussion within the studies on access to technology and whether youth needed to use assistive devices or other supports to participate. Addressing the impact of access to technology is crucial in the context of the digital divide, where inequities in access [82] are often explained by socioeconomic gaps in technology [82]. Research suggests that information technology can help provide people with disabilities with a set of tools to enable their participation and personal development [83,84]. It is important to consider that the cost of adapted technology and assistive technology can be expensive and a potential barrier for people with disabilities accessing the internet, mobile apps, etc [83].

It was interesting that 4 studies explored the role of sex and reported differences in the communication style of youth and their engagement in mentoring programs. These findings have implications for the broader field of research on mentoring, specifically on the relationship between a person's sex and mentoring. Previous work shows that females perceive more barriers to mentorship than males and have more difficulty finding mentoring relationships [85]. However, there is a lack of research comparing the ways in which males and females engage in mentoring relationships and how these interactions influence the effectiveness of mentorship programs.

Future Directions and Implications for Practice

Although our review revealed promising benefits from e-mentoring interventions, more research is needed to explore what types of interventions work best for whom and the optimal delivery formats. Further research is needed to explore whether different delivery formats affect outcomes. Future studies should consider what type of mentor (eg, near-peer with a disability, adult mentor, or youth without a disability) is linked with the optimal outcomes. More rigorous designs are needed to explore formats that were explored only in level 4 studies (eg, email mentoring, group-based interactive websites, virtual world approaches, mobile apps, and Skype video calls). Future research should examine the relationship between socioeconomic and other demographic factors and access to technology in the development of e-mentoring programs for youth with disabilities. Further studies should consider investigating the impact of a person's sex on the ways in which youth with disabilities use e-mentoring programs, comparing potential sex-based difference in effectiveness of interventions, communication, and engagement. Such research is important for increasing the engagement of women in science, technology, and mathematics fields, where both women and individuals with disabilities have long been underrepresented [70]. Finally, more research needs to explore the influence of socioeconomic status on the use of e-mentoring programs and the impact of the digital divide on the accessibility of information communication technology for youth with disabilities participating in e-mentoring programs.

Those designing and implementing e-mentoring programs for youth with disabilities should consider moderating factors such as type of disability, sex, and communication style. Given that many studies demonstrated that various forms of e-mentoring are feasible and acceptable to participants, the next steps should be to consider how to scale up these interventions to larger numbers of participants and various types of disabilities.

Conclusions

The results of this review suggest that e-mentoring is a potentially viable method for improving the accessibility and availability of mentors for children and youth with disabilities. The interventions we reviewed were found to be feasible and useful, and facilitated improved communication in mentor-mentee relationships. The studies reported a range of benefits that addressed many of the challenges faced by individuals with disabilities throughout development, including reduced social isolation, increased self-confidence and self-efficacy, and improved career readiness and decision making. Further studies with more rigorous design are required to identify and compare the effectiveness of the components of e-mentoring interventions (eg, type of mentor, group or one-to-one mentoring, and format of delivery), as well as to understand the influence of the mentee's sociodemographic factors (eg, type of disability, sex, and socioeconomic status) on the impact of e-mentoring programs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy.
[PDF File (Adobe PDF File), 23KB - pediatrics_v1i2e11679_app1.pdf]

Multimedia Appendix 2
Overview of studies.
[PDF File (Adobe PDF File), 71KB - pediatrics_v1i2e11679_app2.pdf]

Multimedia Appendix 3
Scores using the standard assessment criteria for quantitative studies.
[PDF File (Adobe PDF File), 41KB - pediatrics_v1i2e11679_app3.pdf]

Multimedia Appendix 4
Scores using the standard assessment criteria for qualitative studies.
[PDF File (Adobe PDF File), 38KB - pediatrics_v1i2e11679_app4.pdf]

Multimedia Appendix 5
Overview of components of e-mentoring interventions by level of evidence.
[PDF File (Adobe PDF File), 29KB - pediatrics_v1i2e11679_app5.pdf]

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Abbreviations

e-mentoring: electronic mentoring
ERIC: Education Resources Information Center
RCT: randomized controlled trial

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Original Paper

“How Is My Child’s Asthma?” Digital Phenotype and Actionable Insights for Pediatric Asthma

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Abstract

Background: In the traditional asthma management protocol, a child meets with a clinician infrequently, once in 3 to 6 months, and is assessed using the Asthma Control Test questionnaire. This information is inadequate for timely determination of asthma control, compliance, precise diagnosis of the cause, and assessing the effectiveness of the treatment plan. The continuous monitoring and improved tracking of the child’s symptoms, activities, sleep, and treatment adherence can allow precise determination of asthma triggers and a reliable assessment of medication compliance and effectiveness. Digital phenotyping refers to moment-by-moment quantification of the individual-level human phenotype in situ using data from personal digital devices, in particular, mobile phones. The kHealth kit consists of a mobile app, provided on an Android tablet, that asks timely and contextually relevant questions related to asthma symptoms, medication intake, reduced activity because of symptoms, and nighttime awakenings; a Fitbit to monitor activity and sleep; a Microlife Peak Flow Meter to monitor the peak expiratory flow and forced exhaled volume in 1 second; and a Foobot to monitor indoor air quality. The kHealth cloud stores personal health data and environmental data collected using Web services. The kHealth Dashboard interactively visualizes the collected data.

Objective: The objective of this study was to discuss the usability and feasibility of collecting clinically relevant data to help clinicians diagnose or intervene in a child’s care plan by using the kHealth system for continuous and comprehensive monitoring of child’s symptoms, activity, sleep pattern, environmental triggers, and compliance. The kHealth system helps in deriving actionable insights to help manage asthma at both the personal and cohort levels. The Digital Phenotype Score and Controller Compliance Score introduced in the study are the basis of ongoing work on addressing personalized asthma care and answer questions such as, “How can I help my child better adhere to care instructions and reduce future exacerbation?”

Methods: The Digital Phenotype Score and Controller Compliance Score summarize the child’s condition from the data collected using the kHealth kit to provide actionable insights. The Digital Phenotype Score formalizes the asthma control level using data about symptoms, rescue medication usage, activity level, and sleep pattern. The Compliance Score captures how well the child is complying with the treatment protocol. We monitored and analyzed data for 95 children, each recruited for a 1- or 3-month-long study. The Asthma Control Test scores obtained from the medical records of 57 children were used to validate the asthma control levels calculated using the Digital Phenotype Scores.

Results: At the cohort level, we found asthma was very poorly controlled in 37% (30/82) of the children, not well controlled in 26% (21/82), and well controlled in 38% (31/82). Among the very poorly controlled children (n=30), we found 30% (9/30) were highly compliant toward their controller medication intake—suggesting a re-evaluation for change in medication or dosage—whereas 50% (15/30) were poorly compliant and candidates for a more timely intervention to improve compliance to mitigate their situation. We observed a negative Kendall Tau correlation between Asthma Control Test scores and Digital Phenotype Score as −0.509 ($P<.01$).

Conclusions: kHealth kit is suitable for the collection of clinically relevant information from pediatric patients. Furthermore, Digital Phenotype Score and Controller Compliance Score, computed based on the continuous digital monitoring, provide the clinician with timely and detailed evidence of a child's asthma-related condition when compared with the Asthma Control Test scores taken infrequently during clinic visits.

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KEYWORDS

digital phenotype; actionable insights; asthma control level; asthma control test; digital phenotype score; controller compliance score; mobile health

Introduction

Asthma is the second most common chronic disease in the pediatric population. It incurred a total annual direct health care cost of more than US $80 billion dollars burdening the US economy [1]. As of 2016, more than 26 million Americans have been diagnosed with asthma, of which 8.3% are children [2]. Asthma is a multifactorial disease, manifesting many symptoms, which reduce the quality of life. The onset of asthma and the factors that affect its severity and control level vary. Asthma can affect a child's physical and mental well-being. It can lead to reduced activity, missed school days, difficulty in concentrating, feeling isolated from peers, and in extreme cases, emergency room visits, ultimately impacting long-term academic, economic, and physical growth [3]. As such, parents want to know how well controlled their child's asthma is on a regular basis, so that they, with the help of the clinician, can better plan and manage their child's care protocol.

Asthma patients are usually given an asthma action plan to deal with asthma symptoms and a detailed education about triggers and the importance of compliance. It would be helpful for the parent and the clinician to receive information about the child's adherence to care protocol and exposure to factors that can exacerbate the child's asthma in a timely manner. We built the *kHealth system* consisting of *kHealth kit*, *kHealth cloud*, and *kHealth Dashboard*; adapted it for continuous and comprehensive monitoring of a child's symptoms, activity, sleep pattern, potential environmental triggers, and medication compliance; and derived insights to help manage asthma.

The *kHealth kit* consists of a mobile app, provided on an Android tablet, that asks timely and contextually relevant questions related to asthma symptoms, medication intake, reduced activity because of symptoms, and nighttime awakenings; a Fitbit to monitor activity and sleep; a Microlife Peak Flow Meter to monitor the peak expiratory flow and forced exhaled volume in 1 second; and a Foobot to monitor indoor air quality. The *kHealth cloud* stores personal health data and environmental data collected using Web services. The *kHealth Dashboard* interactively visualizes the collected data. In the contemporary clinical protocol, the most relevant information will likely come from an Asthma Control Test (ACT) that is administered during the child's clinic appointment. The ACT score is a recapitulation of the past 4 weeks of the child's health condition; there is considerable concern about its ability to provide a clear picture of the child's current health condition [4,5]. Our kHealth system seeks to remedy this limitation by embodying the digital phenotype.

The term digital phenotype refers to *moment-by-moment quantification of the individual-level human phenotype in situ using data from personal digital devices, in particular, mobile phones* [6]. The data can be collected either by the active involvement of a user, referred to as *active sensing*, or automatically and nonintrusively using sensors, referred to as *passive sensing* [7]. *Digital phenotype* in our study is the data collected through active and passive sensing of a child, resulting from the interaction of the child with the environment and medication using the kHealth kit. Previous studies have reported inaccuracies in a child's self-reporting (in surveys, questionnaire, etc) at the clinic [8,9]. Our kHealth system overcomes this limitation by allowing 24/7 continuous and objective monitoring of a child. Digital phenotype obtained can help the clinician better diagnose, monitor, and manage asthma [6,10].

In this study, we focus on the cohort-level analysis of the data collected from 95 asthmatic children using the kHealth app. To abstract the digital phenotype in a form that is both accessible and can serve as a proxy for the current practice, we define a Digital Phenotype Score (DPS) and Controller Compliance Score (CCS). DPS and CCS are based on the comprehensive physical, environmental, activity, symptomatic, and medication intake data collected from the kHealth system and form the basis for actionable insights. For instance, unlike an ACT score, DPS and CCS together can help the parent and the clinician to intervene, improve the care protocol, change the medication dosage, and take preventative measures as needed—such as avoiding the outdoors and the use of an air filter or dehumidifier in a timely manner.

Methods

Study Recruitment

Study participants were recruited from children (within the age group of 5-17 years) diagnosed with asthma by an asthma specialist at Dayton Children's Hospital (DCH). Study coordinator approached the parents of asthma patients seeking treatment at DCH. The parent, along with the child, consented to participate in our study. The parent provides the consent, and the child provides an assent by signing a consent form to take part in our study and giving permission to obtain their medical details from the electronic medical records (EMRs). The recruitment for the study is random, with the only prerequisite of suffering from asthma. The types of asthma, such as nonpersistent, persistent, exercise-induced, and nonexercise-induced, are not taken into account. A total of 100 study participants, along with a parent or guardian, consented to the ongoing study during December 2016 until July 2018. A total of 95 children of the 100 completed the study, with 5 children still collecting data at the time writing of this study. The child and the parent were given an option to participate either in a 1-month (n=70) or 3-month (n=25) study. The participants who completed the 1- and 3-month study were given an incentive of $50 and $100 gift cards, respectively. Figure 1 describes the study recruitment. Except for the duration of participation, all other aspects of the participants were identical. Each consenting participant was given a demonstration of all the components of the kHealth kit with access to a user guide and tutorial video on the tablet to make it accessible to both the child and the parent. In case of any trouble encountered during the study participation, the contact information of the nurse practitioner was provided to the parent. In case of technical difficulties, contact information of the kHealth team was provided in the user guide to telephonically resolve the issue while keeping the identity of the participant anonymized.

Study Design

This is an observational longitudinal study involving collaboration among researchers from Kno.e.sis—an Ohio Center of Excellence for BioHealth Innovations at Wright State University and DCH, the latter consisting of a clinician and a nurse coordinator. The study was approved by the DCH institutional review board (IRB). The study uses readily available sensors and widely used technologies. The study comprises 30 kits to allow parallel participations of up to 30 children.

Study Kit

kHealth

The kHealth system comprises a kHealth kit, kHealth cloud, and kHealth Dashboard.

kHealth Kit

A kHealth kit, as shown in Figure 2 (more information can be found in Multimedia Appendix 1), consists of an Android tablet hosting kHealth app and a set of sensors (Fitbit, Foobot, and Microlife Peak Flow Meter), which are used by the child. Sections below provide a description of all the sensors and the type of data collected from them. The data are collected using the active and passive sensing techniques. Active sensing refers to the data collection where a child (or a parent) has to actively interact with the technology (eg, answering questions after invoking a mobile app). Passive sensing refers to the data collected without active human interaction with the technology (eg, Foobot [11] sensor in a room automatically collects the indoor air quality data).

Figure 1. Study recruitment detail. ACT: Asthma Control Test; DPS-T: Digital Phenotype Score calculated using Total Symptom Score.

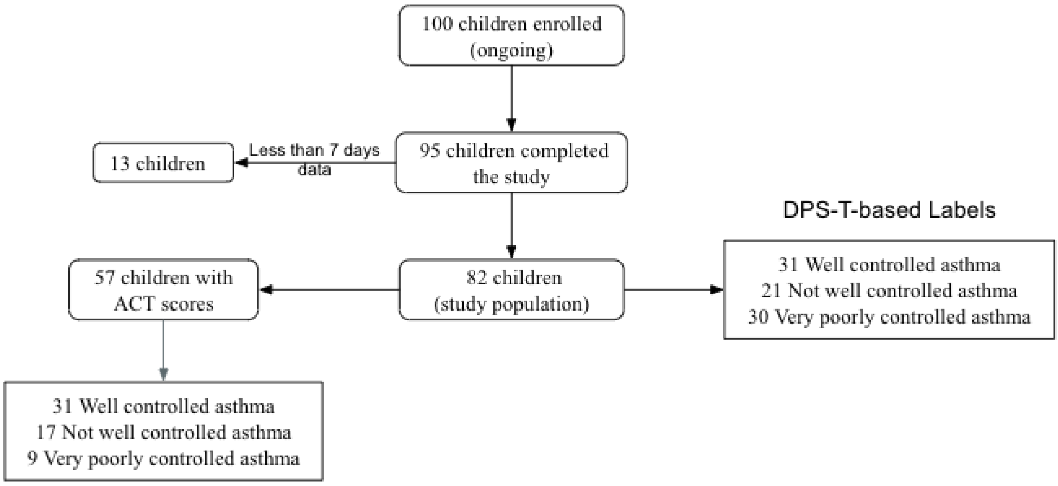


Figure 2. kHealth System.

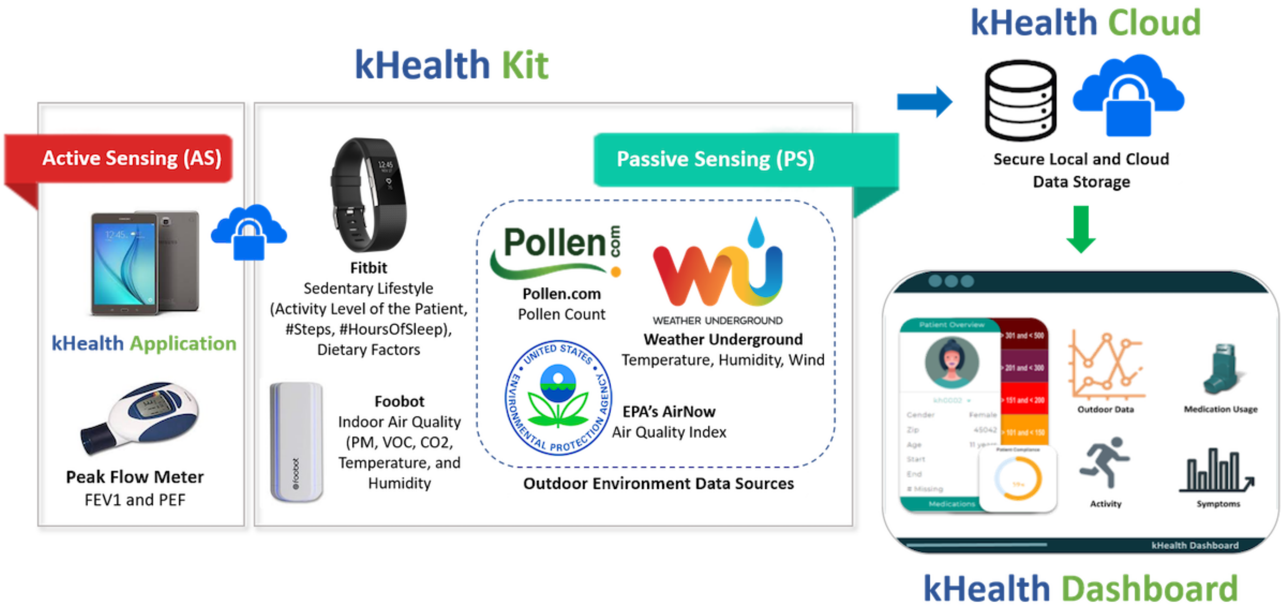


Table 1. kHealth app questionnaire.

kHealth app questions	Multiple-choice options
Are you currently experiencing any of the asthma-related symptoms below?	Cough, wheeze, chest tightness, hard and fast breathing, nose opens wide, cannot talk in full sentences, others
How many times did you take albuterol inhaler today because of asthma symptoms?	1, 2, 3, 4, 5, 6+
Have you had a wheeze, chest tightness, or asthma-related cough today?	Yes, no
How much did asthma or asthma symptoms limit your activity today?	None, a little, most of the day, at least half of the day
Did you take albuterol last night because of a cough or wheeze?	Yes, no
Did you wake up with a cough or wheeze last night?	Yes, no
Rescue medication question. For example, did you take albuterol today?	Yes, no
Controller medication question. For example, did you take Dulera today?	Yes, no

kHealth App

The kHealth app was built on the widely used Android platform [12]. The app was designed in consultation with the clinician, tested with trial patients, and iteratively refined before reaching the current version used in this study [13]. The app asks questions similar to the ACT. The app captures symptoms, medication intake, and activity limitation because of asthma symptoms and nighttime awakenings using a questionnaire that the child is expected to answer twice a day. The app was customized for every child, such as the medication (rescue and controller) information for every child was taken from the EMRs, and the medication intake questions were asked for the prescribed medication only. Table 1 below shows the kHealth app questionnaire.

kHealth Cloud

The data collected from the kHealth kit are synced in real time with Firebase, a Google cloud storage. Firebase provides active data listening for the client-side, which offers data persistence over a network failure and re-syncs to the cloud when the network is restored. The kHealth app uses SQLite as the primary data storage and Firebase as the secondary data storage. Data from Firebase are available to Kno.e.sis researchers and clinicians for real-time analysis. For securing remote data, Firebase provides a set of real-time database rules and user authentication that allow data access control on a per-user basis. Moreover, it is built on the Google Cloud Platform, sharing the same level of data security [14].

kHealth Dashboard

kHealth Dashboard as shown in Figure 3 is a cloud-based platform that integrates and visualizes multimodal data from the kHealth kit [15] (A demo video of the kHealth Dashboard can be found by accessing the link provided in Multimedia Appendix 1). It provides an alternative to the traditional episodic clinician-centric health care by supporting real-time monitoring of a child’s health condition [16]. It is a step toward exploring issues such as the following: Can we predict asthma attacks based on the data collected from the child? Can we understand the causal relationship between symptoms and possible triggers or factors responsible for them? kHealth Dashboard allows us to visually explore the correlations between the child's recorded readings about their condition and environmental data. It also gathers empirical evidence to analyze and monitor disease progression as well as help manage asthma.

Study Variables

Symptom Score

Symptom score (SS) is the measure of the symptoms (cough, wheeze, chest tightness, nose open wide, and hard and fast breathing) experienced by the child during the study period. The study period is defined as the number of days the child took a kHealth app reading. The clinician can use the SS measure to get real-time insight into the child's condition, such as changes in symptoms because of weather or outdoor condition. We used 2 different metrics to calculate a child's SS based on (1) the total number of symptoms experienced by the child during the study period (the total number of symptoms experienced is the same as the total number of symptom questions answered in affirmative per day) and (2) the total number of days the child experienced some symptom during the study period. We define Total Symptom Score (TSS) as the average number of symptoms experienced by the child during the study period. We define Partial Symptom Score (PSS) as the fraction of the number of days the child experienced symptom during the study period.

> Total Symptom Score (TSS) = Number of symptoms experienced by the child/Study period
>
> Partial Symptom Score (PSS) = Number of days the children experienced symptoms/Study period

Rescue Score

The kHealth app collects data on the intake of the rescue medication (short-acting bronchodilators) by asking questions such as Did you take albuterol today? We define Rescue Score (RS) as the number of times the child took the rescue medication during the study period. Usually, children take rescue medication to mitigate or prevent the symptoms.

> Rescue Score (RS)= Number of rescue medication intake by the child during the study period/Study period

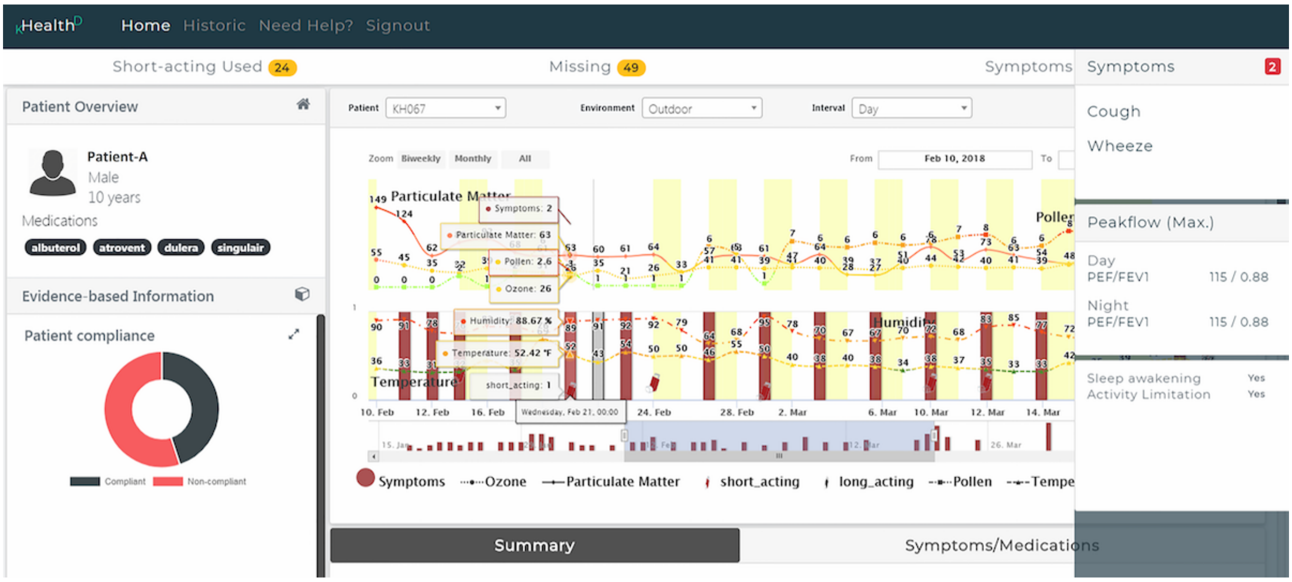
Controller Compliance Score

The kHealth app asks questions (eg, Did you take DULERA today?) about the intake of the controller medication (long-term control medication). Each child is prescribed a controller medication, which they are supposed to take at least once a day. Thus, the CCS is defined as the fraction of the number of days the child took the controller medication during the study period.

> Controller Compliance Score (CSS) = Number of controller medication intake by the child during the study period/Study period

The percentage of children in the well-controlled category increases with the increasing CCS, as shown in Figure 4. The more compliant children are toward their medication, the better controlled is their asthma. Table 2 describes the controller medication compliance threshold. We chose a threshold of 70%. For example, if the child took her/his medication at least 70% of the prescribed duration during the study period (for 1 month [30 days] minimum 21 days and for 3 months [90 days] minimum 63 days), then the corresponding CCS≥0.70 and is the child is classified as *highly compliant*.

Figure 3. kHealth Dashboard Visualizing the Data.



Patient-A
Male
10 years
Medications
albuterol atrovent dulera singulair

Patient: KH067
Environment: Outdoor
Interval: Day
From: Feb 10, 2018

Symptoms: 2
Particulate Matter: 63
Pollen: 2.6
Ozone: 26
Humidity: 88.67 %
Temperature: 52.42 °F
short_acting: 1
Wednesday, Feb 21, 00:00

Symptoms 2
Cough
Wheeze

Peakflow (Max.)
Day PEF/FEV1 115 / 0.88
Night PEF/FEV1 115 / 0.88

Sleep awakening Yes
Activity Limitation Yes

Figure 4. The variation of the percentage of children in the different asthma control level with the Controller Compliance Score.

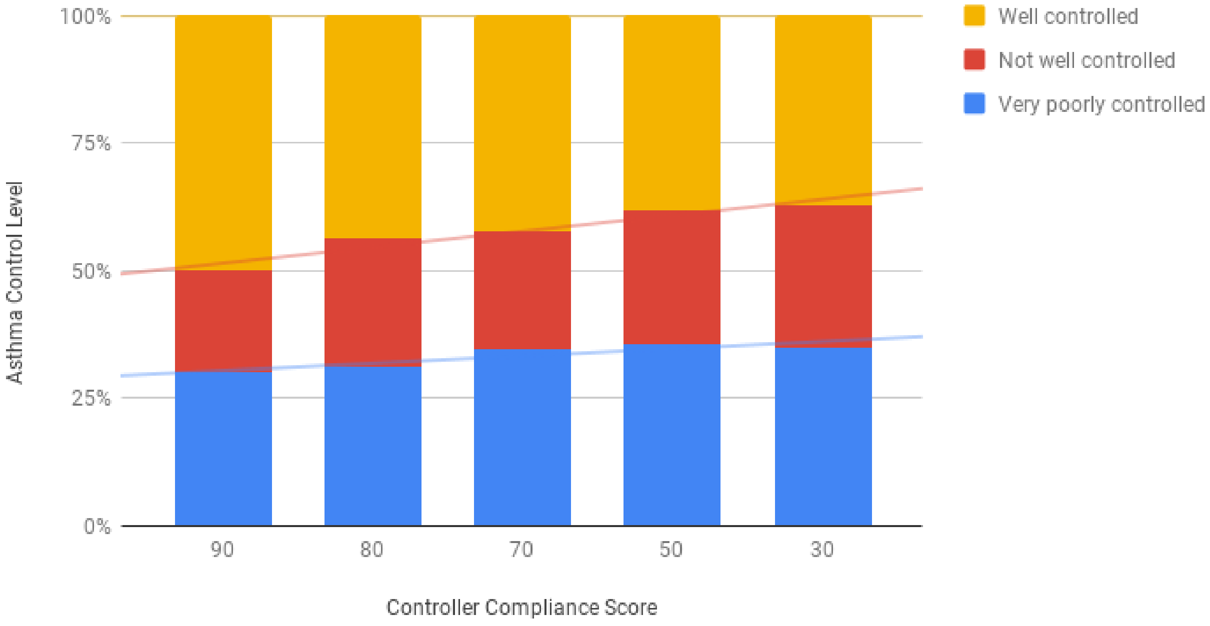


Table 2. Controller Compliance Score thresholds.

Compliance	Controller Compliance Score (CCS)
Highly compliant	CCS≥0.70
Well compliant	0.30≤CCS<0.70
Poorly compliant	CCS<0.30

Activity Score

The Activity Score (AcS) is the number of days the child had restricted activity during the study period. The kHealth app asks a multiple-choice question: *How much did asthma symptoms limit your activity today?* with 4 options: none, a little, half of the day, and most of the day. The options are given a weight on a scale of 0-3, respectively.

> Activity Score (AcS) = Summing over the days in the study period (activity restriction presence option weight)/Study period

Awakening Score

The Awakening Score (AwS) is the number of nights the child woke up because of asthma symptoms during the study period. The kHealth app asks a multiple-choice question: *Did you wake up with wheeze, cough, or any asthma-related symptoms?*

> Awakening Score (AwS) = Number of nights the child woke up with asthma symptoms during the study period/Study period

Asthma Control Test Score

ACT is a short multiple-choice questionnaire consisting of 5 questions: about a child's symptoms, nighttime awakenings because of symptoms, number of days the child missed school because of symptoms, intake of rescue medication, and the child's rating about their asthma control in the past 4 weeks. Each question is given a score of 1-5, with 1 being the worst and 5 being the best. The ACT score is calculated by adding the scores for each question. Its score helps the clinician classify the child's asthma as well controlled, not well controlled, or very poorly controlled [17]. The ACT score based asthma control level label varies with the age group. For children less than 12 years, if the ACT score is ≤12, the child's asthma is *very poorly controlled*. If the ACT score is ≥13 and ≤19, the asthma is *not well controlled*, and if the ACT score is ≥20, the asthma is *well controlled*. For the children aged ≥12 years, if the ACT score is ≤15, the child's asthma is *very poorly controlled*. If the ACT score is ≥16 and ≤19, the asthma is *not well controlled*, and if the ACT score is ≥20, the asthma is *well controlled*.

Digital Phenotype Score

> Digital Phenotype Score Total (DPS-T) = Total Symptom Score + Rescue Score + Activity Score + Awakening Score
>
> Digital Phenotype Score Partial (DPS-P)= Partial Symptom Score + Rescue Score + Activity Score +Awakening Score

The DPSs (DPS-T and DPS-P, discussed below) capture an aggregate of each of the contributing digital phenotypes that impact the child's health. This is in the same vein as ACT, which tries to quantify the child's asthma control based on responses to the 5 asthma condition–related questions and Patient Health Questionnaire-9 (PHQ-9), which tries to quantify patients' depression severity based on their responses to the 9 mental health condition–related questions [18,19]. The DPSs are a digital measure of the *quality of life* of the child appropriate for the kHealth context and can be used as a succinct proxy to determine the control level. We try to capture the intuition that the higher the manifestation of asthma signs, the worse the control. The more occurrences of symptoms, increased intake of rescue medication, restriction of daily activities and nighttime awakenings, and the worse is the child feeling, the poorer is the asthma control. We propose to define the scores to reflect the cumulative effect of various negative factors impacting a child's health and its manifestation, as measured by symptoms such as cough and wheeze, reduced physical activity, nighttime awakenings, and intake of rescue medication, either to remedy symptoms or to prevent them. Specifically, we consider 2 different alternatives for computing the score each with its own pros and cons: (1) DPS-T to capture the total number of asthma episodes by summing the TSS, RS, AcS, and AwS, which we regard as a fine-grained reflection of the child's suffering, and (2) DPS-P that substitutes the TSS with a PSS in DPS-T (ie, DPS-P=DPS-T − TSS + PSS) to better match the ACT scoring approach to determine the control level, for fair comparison and validation with respect to the current practice. Similar to the ACT scoring, our approximation does not have differential weighing of symptoms (such as cough < wheeze < chest tightness). Although this may be adequate to obtain a coarse-grained classification for control level, it may not truly reflect the relative *quality of life* enjoyed by the child faithfully. For instance, a child having 10 coughs each day for 2 days may be better off than 10 coughs over 3 days. DPS-T better captures this intuition than DPS-P. However, ACT scores, DPS-T, and DPS-P do not satisfactorily capture the fact that someone having wheezing, shortness of breath, and chest tightness on a day may be significantly worse off than someone coughing several times a day. In fact, the former may lead to an asthma attack, even requiring an emergency hospital visit compared with the latter. In this study, we evaluate DPS-T and DPS-P as an approximate measure of the asthma-related health condition of the child.

The National Heart Lung Blood Institute (NHLBI) provides a guideline to classify the child's asthma control level as *very poorly controlled*, *not well controlled*, and *well controlled*. We used the NHLBI guidelines and the data collected from the kHealth app to determine the child's control level by developing a comparable threshold for DPS-P and DPS-T.

Using the NHLBI guidelines given in Table 3 [20], we have developed thresholds for DPS (DPS-P and DPS-T) as shown in Table 4 (eg, if the DPS≥1, then the child's asthma is very poorly controlled). The thresholds for the 3 control levels have been chosen to make the DPS-P and ACT scores comparable when they are available over the same period. The control levels obtained based on DPS-T using the same thresholds seem to be relatively pessimistic, but in reality, they have the potential to capture the child's reaction to asthma triggers over the day at a fine-grained level.

Table 3. Modified National Heart Lung Blood Institute asthma control level classification guide (given by National Heart Lung Blood Institute).

Component of control	Age in years	Level of asthma control		
		Well controlled	Not well controlled	Very poorly controlled
Impairment				
Symptoms	0-11	≤2 days/week but ≤1 time a day	>2 days/week or multiple times on ≤2 days/week	Throughout the day
	≥12	≤2 days/week	>2 days/week	Throughout the day
Nighttime awakenings	0-4	≤1 time a month	>1 time a month	>1 time a week
	5-11	≤1 time a month	≥2 times a month	≥2 times a week
	≥12	≤2 times a month	1-3 times a week	≥4 times a week
Interference with normal activity	All	None	Some limitation	Extremely limited
Rescue medication; use for symptoms	All	≤2 days/week	>2 days/week	Several times per day

Table 4. The thresholds for the classification of asthma control levels for both Digital Phenotype Score calculated using Partial Symptom Score and Digital Phenotype Score calculated using Total Symptom Score.

Asthma control level	Digital Phenotype Score (DPS)
Very poorly controlled	DPS≥1
Not well controlled	0.28≤DPS<1
Well controlled	DPS<0.28

Data Availability

The study took comprehensive design- and technology-supported steps to ensure Health Insurance Portability and Accountability Act (HIPAA) compliance, privacy preservation, and data security. For example, each consented child was given a kHealth-ID by the nurse coordinator and retained so that child identifiable information did not leave the hospital clinic [21]. Throughout the data collection, only the deidentified data were made available for analysis by the kHealth system. A child's real identity was not recorded, and any data exchange between DCH and other researchers ensured that the child's identity information did not leave DCH. The data used for the study cannot be made publicly available because of HIPAA and other restrictions imposed by the approved IRB protocol. The dataset is accessible only to the clinician and the researchers involved in the study. Furthermore, it is available to the researchers only in anonymized form. All team members have completed relevant Collaborative Institutional Training Initiative program courses.

Data Analysis

We performed a descriptive analysis of the data with IBM SPSS Statistics version 24 (IBM Corporation). We removed 13 children from our analysis who had data for less than 7 days to follow the NHLBI guideline, which requires a minimum of a week's data to determine the child's asthma control level [20]. This study presents an analysis of 82 children reporting data for more than 7 days. ACT scores were available from the EMRs for 57 of these children and were used for validation of the asthma control levels, calculated using the DPSs. We used Kendall Tau correlation metric to analyze the concordance between the asthma control level labeled using ACT scores and DPSs.

Results

The average compliance of the kHealth kit was 75% (range: 9-100, SD=23). Of the children in our study cohort, 66% (54/82) were found to be highly compliant, 31% (25/82) were well compliant, and 4% (3/82) were found to be poorly compliant toward taking the kHealth app reading. The highly compliant and well compliant are defined using the kHealth app and taking a reading for at least 70% and 50%, respectively, of the study period. We classified the 82 children involved in our study into their asthma control level using the DPS-P and DPS-T. Using DPS-P, 30.5% of the children were classified as very poorly controlled, 26.8% as not well controlled, and 42.7% as well controlled. DPS-P classification (using scoring and threshold) adapts the ACT approach in the context of kHealth app. On the basis of DPS-T, 37% of the children were classified as very poorly controlled, 26% as not well controlled, and 38% as well controlled. Effectively, DPS-T classified a higher number of children as very poorly controlled or not well controlled as compared with DPS-P.

We used ACT scores recorded in the EMRs to understand how it corresponds to our classification based on the 2 DPS scales. ACT scores were available for 57 children of the 82 children who qualified for detailed evaluation. Tables 5 and 6 provide classification details using DPS-T and DPS-P based on adapted thresholds.

Table 5. The relationship between Asthma Control Test and the 2 versions of the Digital Phenotype Scores (N=57).

Asthma control labels	ACT[a] score, n (%)	DPS-P[b], n (%)	DPS-T[c], n (%)
Very poorly controlled	9 (16)	20 (35)	23 (40)
Not well controlled	17 (30)	15 (26)	16 (28)
Well controlled	31 (54)	22 (39)	18 (32)

[a] ACT: Asthma Control Test.

[b] DPS-P: Digital Phenotype Score calculated using Partial Symptom Score.

[c] DPS-T: Digital Phenotype Score calculated using Total Symptom Score.

Table 6. Asthma Control Test and Digital Phenotype–based classification (N=57) where VPC is very poorly controlled asthma, NWC is not well controlled asthma, and WC is well controlled asthma. .

Asthma control labels	Children classified based on ACT[a] score, n	Children classified based on DPS-P,[b] n	Children classified based on DPS-T,[c] n
Very poorly controlled (VPC)	9	VPC=7	VPC=8
		NWC=1	NWC=0
		WC=1	WC=1
Not well controlled (NWC)	17	VPC=11	VPC=13
		NWC=4	NWC=3
		WC=2	WC=1
Well controlled (WC)	31	VPC=2	VPC=2
		NWC=10	NWC=12
		WC=19	WC=17

[a] ACT: Asthma Control Test.

[b] DPS-P: Digital Phenotype Score calculated using Partial Symptom Score.

[c] DPS-T: Digital Phenotype Score calculated using Total Symptom Score.

As seen in Table 7, the DPS-P scale correctly classifies 7 out of 9 children as very poorly controlled. There was only 1 child with an ACT score of 11 (which is very poorly controlled) who was classified as well controlled according to DPS-P (=0.19) and not well controlled according to DPS-T (=0.39). We observed 2 children with the same DPS-P score of 1.33 (very poorly controlled), but they had 2 different ACT scores of 15 and 19, respectively, but both imply not well controlled. Although their DPS-P was the same, their DPS-T are 1.43 and 2.32, respectively, showing that the second child's asthma condition is worse than the first one. We observed 2 children with DPS-P of 0.74 and 0.72, respectively, both not well controlled according to DPS-P criteria. According to their ACT, the same 2 children were classified as very poorly controlled (ACT score=13) and well controlled (ACT score=24). Furthermore, their DPS-T was 1.70 and 0.76, respectively. The latter's scores are consistent with the DPS-P but also show that the first child is relatively worse off than the second child. Note also that differently classified children in the 3 categories were deployed in the allergy season, accounting for a higher SS during the allergy season, which was not captured by the ACT. Thus, DPS has the potential to provide more contemporary and timely gauge of a child's asthma control.

Next, we provide further observations based on DPS-T and CCS. We observed that 50% of very poorly controlled children were poorly compliant, 20% well compliant, and 30% highly compliant. In the not well-controlled children cohort, 42.9% were poorly compliant, 28.6% well compliant, and 28.6% highly compliant. The well controlled children were 48.4% poorly compliant, 16.1% well compliant, and 35.5% highly compliant.

Figure 5 shows the distribution of ACT score and DPS-P. Figure 6 shows the distribution of ACT score and DPS-T.

To better quantify the relationship between the distribution of ACT scores and the DPS, we used Kendall Tau correlation metric to analyze the concordance between them [22,23]. We observed a negative correlation between ACT scores with both DPS-T and DPS-P and calculated them as −0.509** and −0.509**, respectively, ($P<.01$). The negative correlation accords well with that the fact the ACT scores and DPSs are inversely related. Unsurprisingly, we also observed a positive correlation between DPS-T and DPS-P as 0.921** ($P<.01$).

We also explored potential reasons for the varying asthma control by analyzing CCS, reflecting how well a child follows the asthma management protocol in terms of controller medication intake. We observed that 47.6% of the study participants were poorly compliant (according to CCS), 20.7% were well compliant, and 31.7% were highly compliant toward their controller medication use.

Figure 5. Distribution of Asthma Control Test score and Digital Phenotype Score calculated using Partial Symptom Score across the study population.

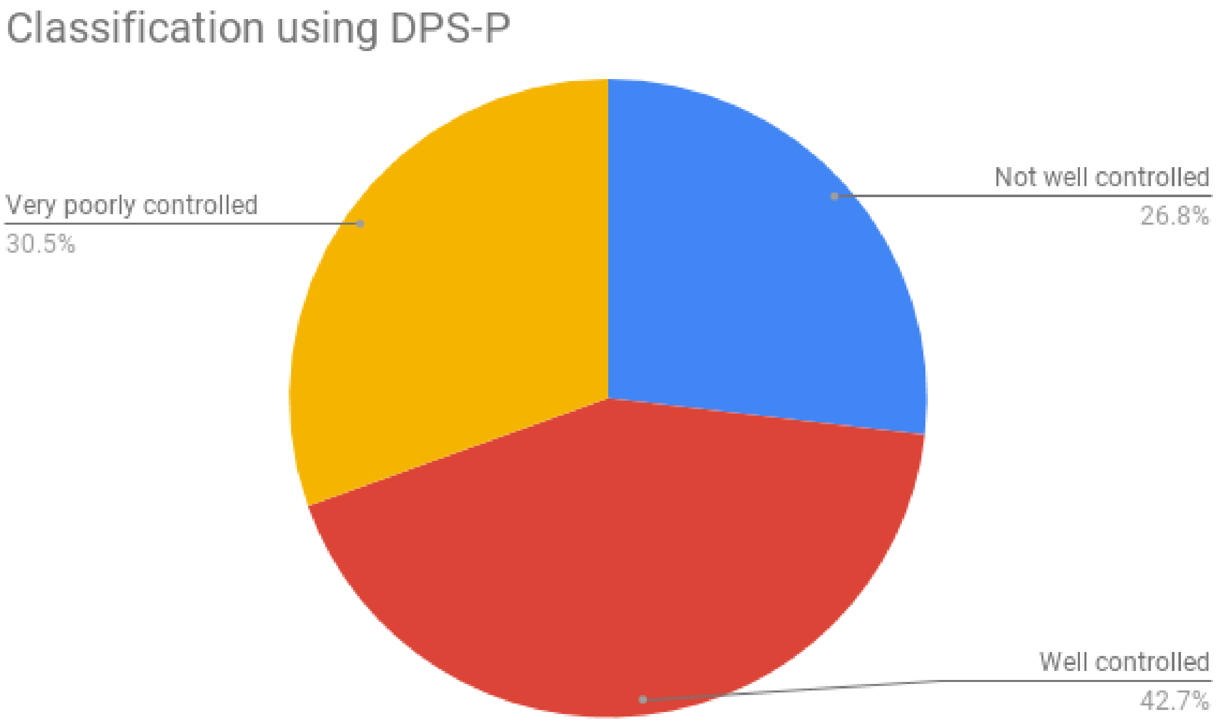
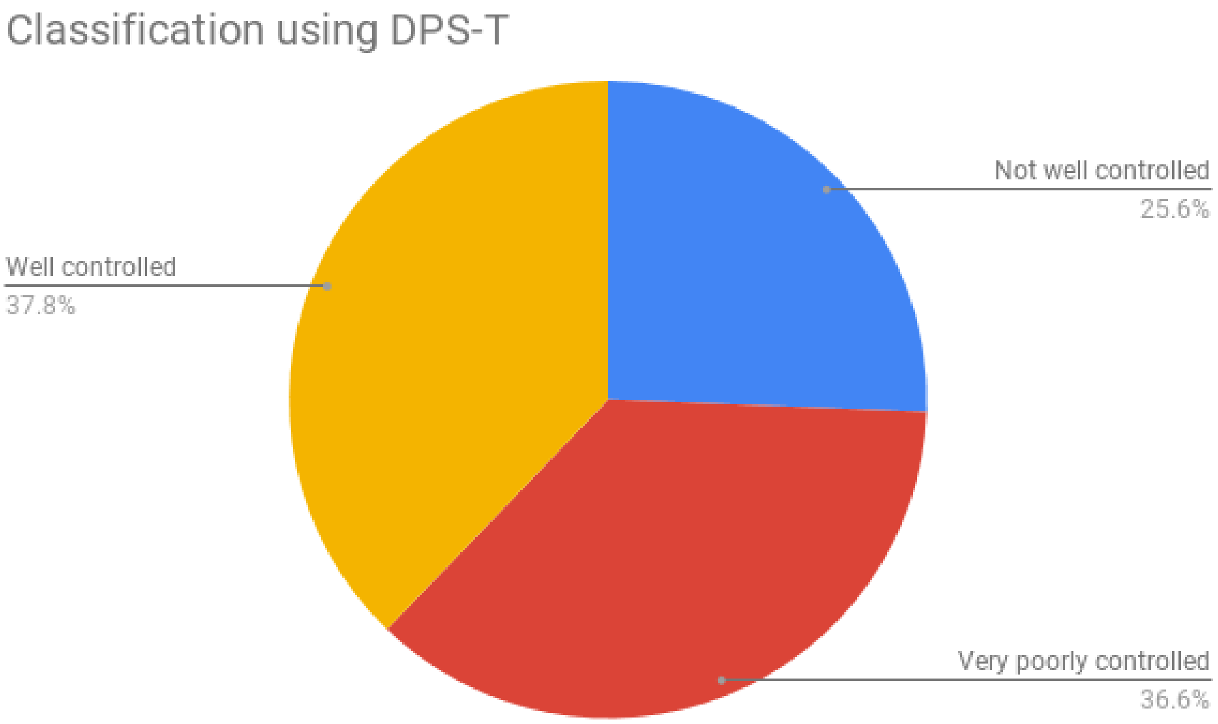


Figure 6. Distribution of Asthma Control Test Score and Digital Phenotype Score calculated using Total Symptom Score across the study population.



Discussion

Principal Findings

Suboptimal adherence to asthma therapy in children has been shown to result in poor disease control and increased hospitalization. Our study highlights this important issue, demonstrating a 50% compliance with controller medication in a cohort of children under the care of asthma specialists, which can be improved. In addition, almost 66% compliance with kHealth kit was achieved in this cohort. The 66% compliance with kHealth kit in this cohort appears to be highly encouraging, especially given the relative complexity of the kit (eg, need to connect with Wi-Fi or use a dongle) and the fact that DCH generally serves families in the medium to lower socioeconomic measures, including inner city. The kit compliance is the measure of the number of days the child took the kHealth kit reading during the deployment duration (1 or 3 months). This shows the potential to improve adherence by motivating children and parents. Several studies have demonstrated an increased adherence when data from electronic monitoring were shared with participants [9]. In children with asthma, an improvement in the use of preventive medication has been demonstrated when feedback was provided at each clinic visit [24]. The clinicians and researchers can be involved in patient-led and patient-centered digital health design [25]. It can encourage patients to share their data with their clinician or the researchers involved. It can be used to learn about the patient's online networks and educate the patient by connecting with them and strengthening the network. The kHealth study offers an intervention for improving asthma control level as determined using the DPS. It demonstrates an opportunity for timely identification of children who are not well controlled or poorly controlled, and on the basis of their compliance, offer guidance for further intervention. For instance, for poorly compliant children, the parent or guardian can provide timely reminders to improve compliance for taking controller medication. In fact, this is also an opportunity to automatically generate friendly and timely reminders in a later version of our kHealth app, IRB approval permitting. For well complaint children, the clinician may decide to reevaluate medication and its dosage.

Several reasons can account for the discrepancy between assessments based on the ACT score and the DPS-P/DPS-T. The primary reason seems to be that the ACT was administered before the deployment of the kHealth kit and, in a number of cases, at the onset of the allergy season. Hence, there can be a mismatch between the relatively good asthma control level during trigger-free environment as compared with the asthma control level during allergy season. Furthermore, these same children are unlikely to return for a follow-up appointment (because their asthma is well controlled according to ACT and as dictated by the current practice are not required to take ACT at the end of the study period), and hence, we have no way to obtain ACT scores specifically summarizing the child's condition during the allergy period for these specific study data. In addition, the ACT scores are based on child's self-reporting and memory of episodes of past 4 weeks, running the risk of missing out on the fine-grained details that the kHealth can capture reliably and effortlessly (with its passive components). The kHealth app asks questions similar to ACT twice a day, providing a detailed day-to-day insight into the child's condition. ACT scores provide an abstract, subjective, and cumulative picture of the child, whereas the kHealth app additionally provides an objective and a more granular insight into the child's environment, activities, medication intake, and so on. Also note that ACT questions abstract away occurrences of a number of symptoms per day by considering only the number of days the symptoms appear, whereas DPS-T captures such additional fine-grained detail. The DPS-P was developed to approximate and generalize information sought in ACT questionnaire. Thus, DPS-T is able to distinguish between 2 children who experience a different number of symptoms every day that DPS-P is not sensitive to. As with ACT, we still do not distinguish the acuteness of different symptoms with respect to asthma. Using the DPS-based control levels and CCS, we can provide actionable insights (interventional steps) devised in consultation with our clinician partner as described in Table 7.

Limitations

Children were enrolled on a first-come-first-serve basis, as the study was designed to demonstrate (1) feasibility of the kHealth system approach involving acceptability and usability, (2) robustness of the kHealth kit, quality, and consistency of measurements that provide clinically relevant data not currently available to the clinician (including assessing the relevance of patient-generated data and environmental data), and (3) maximize recruitment. Specifically, we had not planned the kHealth kit deployment for a child to coincide with their asthma exacerbation season or only in allergy season. We also did not deploy the kit for a longer duration (ie, half a year or year round) using the current IRB-approved protocol so as to straddle both nonallergy and allergy seasons to contrast the behaviors on normal days from allergy exposure days.

Several future options can further increase compliance, such as (1) use of more integrated sensors if the cost is acceptable [26], (2) higher monetary incentive for participation, (3) nonmonetary incentive including the clinician’s feedback during a follow-up consult, and (4) more close-up monitoring such as nurse coordinators calling the parent of the children who are delinquent in using the app during the early days of the participation.

Table 7. Actionable insight using Digital Phenotype Score and Controller Compliance Score.

Controller compliance	Very poorly controlled	Not well controlled	Well controlled
Highly compliant	Increase the medication dosage or change/add medication. Identify environmental triggers for mitigation.	Increase the medication dosage or change/add medication. Identify environmental triggers for mitigation.	Maintain therapy. Consider changing the medication or its dosage.
Well compliant	Increase the medication dosage or add medications; provide appropriate preventative suggestions.	Increase the medication dosage or add medications; provide appropriate preventative suggestions.	Maintain therapy. Consider changing the medication or its dosage.
Poorly compliant	Identify barriers to adherence and intervene.	Identify barriers to adherence and intervene.	Reassess diagnosis and modify therapy.

Children were given ACT before kHealth kit deployment, but the ACT was not repeated after the kHealth study period. Moreover, 57 of the 82 cohorts had recorded and available ACT scores. These factors made it difficult to more comprehensively validate our diagnosis based on the digital phenotype approach (DPS-P and DPS-T) against the ACT. Our extensive use of sensors and technology to collect a large variety of data, although novel, had resulted in initial challenges for reliable collection of data, ease of deployment, and use with implications on child compliance. To address these issues, the app underwent multiple design iterations to improve the data retention, usability in terms of intended functionality and connectivity, compliance, and reliability on passive sensing. In particular, 1 sensor used for nitric oxide measurement during the initial trial was removed by the manufacturer from the market and was replaced by the peak flow meter. The accuracy and usefulness of a number of sensors were assessed before starting the study [11].

Conclusions

We have shown that the kHealth app is robust and reliable for use by the pediatric patient and can provide meaningful information to a clinician. We were able to clearly determine, at the cohort level, the relative distribution of children with different ACT scores into different control-level classes, as classified by digital phenotype approach. We also have evidence that tracking the children can not only shed light on their health condition but also provide actionable insight based on their adherence to asthma care plan. Specifically, we expect the digital phenotype and compliance data to be able to provide clinicians with detailed evidence much more transparently and in a more timely manner than the ACT. kHeath asthma was an observational study and lacked an intervention arm. Future trials assessing the impact of feedback derived from digital monitoring on adherence with asthma therapy in children are needed.

Future Work

We plan to conduct a follow-up study that evaluates children over longer periods, covering both allergy and nonallergy seasons. We would like to identify factors affecting asthma at a personalized level as a means to detect the triggers that cause the asthma-related symptoms, monitor the control level, and predict the potential for asthma exacerbation to minimize emergency room visits. This can also help us educate parents and children to improve asthma management and to empower clinicians via an evidence-based approach to obtain better outcomes for each child. We expect the digital phenotype approach and the monitoring of controller medication compliance developed here to be useful in modifying the care protocol and will use them to design a follow-up study as an interventional step. At a broader level, we seek to enhance health care and chronic disease management by aggregating, analyzing, and personalizing the use of relevant physical, cyber, and social data obtained from wearables, sensors, mobile apps, EMRs, Web-based information, and social media. We also seek to develop tailored health management strategies suitable for all ages and at different levels, including self-monitoring, self-appraisal, self-management, intervention, prediction, and tracking disease progression, as identified in our Augmented Personalized Healthcare approach [27,28]. Ultimately, we expect evidence-based disease management to help in reducing the overall cost of care while simultaneously improving quality of life.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
kHealth Wikipedia and kHealthDash Demo Video.
[PDF File (Adobe PDF File), 20KB - pediatrics_v1i2e11988_app1.pdf]

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Abbreviations

ACT: Asthma Control Test
AcS: Activity Score
AwS: Awakening Score
CCS: Controller Compliance Score
DCH: Dayton Children’s Hospital
DPS: Digital Phenotype Score
DPS-T: Digital Phenotype Score calculated using Total Symptom Score
DPS-P: Digital Phenotype Score calculated using Partial Symptom Score
EMR: electronic medical record
HIPAA: Health Insurance Portability and Accountability Act
IRB: institutional review board
NHLBI: National Heart Lung Blood Institute
PSS: Partial Symptom Score
RS: Rescue Score
SS: symptom score
TSS: Total Symptom Score

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Original Paper

Smartphones for Real-time Assessment of Adherence Behavior and Symptom Exacerbation for High-Risk Youth with Asthma: Pilot Study

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Abstract

Background: Youth with asthma who have poor medication adherence, have limited access to care, and are frequently seen in the acute care setting are often termed “high risk.”

Objective: This study aimed to design and test the feasibility of using smartphone technology to assess contextual factors that may impact changes in daily medication adherence and to identify new symptom episodes among high-risk youth with asthma in their home environment.

Methods: Youth aged 8-17 years with high-risk asthma from 2 children’s hospitals were eligible for the 2-month study. An app was downloaded on participants’ phones at enrollment. Daily text message (short message service) reminders were sent to complete ecological momentary assessment of asthma symptoms and other contextual factors such as emotional state using the app. Bluetooth inhaler devices were used to record timestamps of inhaler use with the ability to review and manually enter data. The acceptability was assessed with surveys, key informant interviews (KII), and frequency of days with asthma data. KII data were used in an iterative design approach to identify challenges, strengths, and suggestions for maximizing use. Generalized linear mixed modeling was used to preliminarily explore contextual factors associated with changes in daily adherence.

Results: We enrolled 14 children aged 8-16 years (13/14, 93% were African Americans). Over the 2-month study period, participants reported coughing (42/110, 38%), wheezing (8/111, 7%), chest tightness (9/109, 8%), boredom (57/109, 52%), and 10 new asthma symptom episodes. The controller medication adherence was 30%, which increased significantly on days with asthma symptoms or boredom. Data were received on 89% (606/681) of study days. Surveys and KIIs suggest acceptability among youth and their caregivers. Challenges reported during the study included lost or damaged phones and available memory.

Conclusions: Youth and their caregivers reported the acceptability of using smartphones for real-time asthma monitoring. Overall, the controller medication adherence was low but increased significantly on days with reported asthma symptoms or boredom, suggesting that daily contextual factors may be associated with a change in the adherence behavior.

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KEYWORDS

children; ecological momentary assessment; medication adherence; medication monitoring device; mHealth; mobile phone; symptoms; youth

Introduction

Asthma impacts the lives of 7 million children in the United States costing US $9 billion annually with emergency department and hospital admissions accounting for half of these costs [1-4]. Children with frequent emergency department and hospital visits are often termed “high risk” and more likely to be from a minority race or ethnicity and experience unique barriers such as decreased access to care and more severe disease [5]. Uncontrolled asthma and frequent exacerbations not only negatively impact health but also the quality of life and school attendance, and contribute to missed parental work days [6,7]. Effective preventive care strategies exist to control asthma and prevent its negative outcomes. However, these treatments are seldom delivered with satisfactory adherence among high-risk youth with asthma [8]. Medication adherence among children is further complicated as responsibility for controller inhaler medication delivery gradually transitions from parents to youth. Less than 20% of children aged 7 years are responsible for asthma medication self-management compared with 100% of 19-year-olds’ with asthma [9].

Barriers to controller medication adherence among youth with asthma include forgetfulness, poor asthma knowledge and false beliefs, child avoidance of inhaler use at school, and parental stress with medication delivery [10-14]. Less is known about other social and emotional contextual factors (eg, anger, boredom, and symptoms), and how changes in these factors over time impact the day-to-day adherence behavior for youth with asthma. Emotional factors, such as anger or panic, are frequently reported in association with asthma symptoms, but their effect on asthma self-management including adherence is poorly understood [15,16]. Daily experiences such as mood and motivation have been shown to impact medication adherence in other disease states [17]. Previous studies examining effects of contextual factors on the asthma medication adherence have been based on retrospective surveys, self-reported adherence, and asthma diaries, which are time-consuming, potentially biased, and costly. The adoption of smartphones may offer a solution.

Nearly 75% of US youth have or have access to a smartphone, 92% report going online daily with any mobile device, and 24% report going online “almost constantly” [18]. Ecological momentary assessment (EMA) is an established technique developed within behavioral sciences that enables researchers to monitor disease symptoms, emotional state, and other contextual factors frequently in a real-time natural environment avoiding recall bias [19,20]. The patient-reported inhaler use collected through the EMA has been correlated with validated severity self-report measures (eg, Asthma Control Test) and used in clinical trials with smartphone-based interventions [20,21]. Medication adherence devices previously used in clinical trials are now emerging as a practical tool for clinical practice as they readily connect with smartphones via Bluetooth technology, avoiding inaccuracies associated with self-report [22]. This emerging adherence technology combined with the near-universal adoption of smartphones enables real-time assessments of medication use and patient symptoms and mood, reducing the required effort and cost of attaining real-time assessments of youth with asthma, which may facilitate a better understanding of factors influencing daily changes in adherence behavior [23].

This study aimed to design and pilot-test the feasibility of the Smartphone Asthma Monitoring System (SAMS) that utilizes Bluetooth inhaler monitoring and EMA of contextual factors for youth with high-risk asthma. We used an iterative design approach to maximize participant acceptability among high-risk youth with asthma and their families to address specific barriers to using the technology. Secondarily, this study aimed to explore contextual factors that may impact daily adherence behavior (eg, anger, boredom, or asthma symptoms), as well as understand the utility of the collected data for the identification of newly symptomatic patients.

Methods

Study Population

Youth aged 8-17 years were eligible for participation in this 2-month study. The inclusion criteria were as follows: (1) high-risk asthma, defined as patient having emergency department or hospital visit for asthma in the previous 12 months or the child’s primary asthma provider in the outpatient setting having the opinion that the youth is high risk for future asthma visits to the emergency department or hospital owing to concern for noncompliance or poorly controlled asthma; (2) prescribed a controller and rescue medication compatible with Bluetooth inhaler cap; (3) caregiver or youth own and are able to use a smartphone compatible with Bluetooth devices; (4) English speaking; (5) identified primary care provider with at least one visit in the last year; and (6) ≥1 identified caregiver present for enrollment. This study was approved by the Institutional Review Board at the Medical University of South Carolina.

mHealth Platform

Overview

The SAMS team used an iterative design process with frequent youth, caregiver, and provider engagement to develop a secure mHealth platform. The platform includes a smartphone app (Android operating system) and Bluetooth inhaler caps for enrollees and a Web-based portal for providers or investigators. The app serves the following 4 major functions: (1) manual medication use entry; (2) EMA questionnaire completion; (3) access to inhaler use history; and (4) tracking study compensation (Figure 1).

Figure 1. Screenshot of the Android smartphone app home screen. Image Source: Ronald J Teufel II.

Table 1. Reported asthma symptoms and mood association with changes in daily adherence.

Ecological momentary assessment	Change in adherence[a]			
	Not at all	A little	A lot	Extremely
Are you coughing?	Reference	+6.8% (−3.3% to 16.9%)	+10.5% (−19.1% to 40.1%)	N/A[b]
Are you wheezing?	Reference	+1.0% (−15.0% to 17%)	N/A	N/A
Does your chest feel tight?	Reference	+8.0% (−7.4% to 23.5%)	N/A	N/A
Are you stressed?	Reference	+4.1% (−10% to 18.2%)	N/A	−1.7% (−42.4% to 39.1%)
Are you angry?	Reference	+7.3 % (−9.2% to 23.7%)	+11.1% (−30.0% to 52.3%)	+7.4% (−16.9% to 31.7%)
Are you bored?	Reference	+2.4 (−7.3 to 12.1)	+11.3 (−16.8% to 39.3%)	+20.3 (2.4% to 38.2%)[c]
Are you happy?	+4.5% (−15.2% to 24.1%)	−2.6% (−15.8% to 10.7%)	+3.1% (−6.5% to 12.7%)	Reference
Are you relaxed?	+3.9% (−12.5% to 20.3%)	+0.4 (−14.9% to 15.7%)	−0.8% (−11.1% to 9.4%)	Reference

[a] Estimates were obtained from generalized linear mixed modeling accounting for the longitudinal nature of data, with patients included as random effect.

[b] N/A: Not applicable.

[c] P=.03.

Ecological Momentary Assessments

Our team of asthma providers and behavioral scientists developed EMA questions to assess youth symptoms (eg, coughing, wheezing, and chest feeling tight) and contextual factors, such as emotional state (eg, stressed, angry, bored, happy, and relaxed), relevant to asthma or adherence behavior. To help ensure question clarity, we piloted EMA questions with 3 youth aged 8-15 years and their parents in a small group session before study recruitment. The app was designed to enable youth and caregivers to answer EMA questions securely through their smartphone with minimal effort by clicking the "Questions" tab within the app. Table 1 and Multimedia Appendix 1 list the specific questions including the 4-point Likert scale.

Bluetooth Inhaler Caps

At enrollment, Bluetooth inhaler caps (CareTRX, Cambridge, MA) were attached to both rescue and controller inhalers, paired with the child's or caregiver's smartphone, and successful transfer of data was assessed. Enrollees were instructed to use the inhalers with the cap attached and transfer the cap if a new inhaler was obtained. The caps can store up to 400 inhaler use events. Once the smartphone and cap were within the Bluetooth range (approximately 15-20 feet), the inhaler use data automatically downloaded to the phone. The timestamps were immediately transferred to the Web-based portal and were viewable within the SAMS app in the "Inhaler History" tab. Participants were permitted to enter controller or rescue medication use manually (under the tab "Medication taken") to address situations in which Bluetooth caps were not communicating with the smartphone or in the event of other barriers to data transfer.

Web-Based Portal for Providers

A Web-based portal was designed for providers to document and store enrollment information (eg, email, telephone number, and study identification number) and enable review of youth asthma data in real time. The app securely transferred all data to the Web-based portal on an encrypted server. The portal has the capability to automatically process data and send preprogrammed reminders (eg, inhaler use or study protocol reminders) or reports (eg, adherence or symptoms reports) to patients, caregivers, or providers through email, smartphone reminders, or short message service (SMS) text messages.

Study Design

Enrollment and Procedures

Recruitment occurred from 2 university children's hospitals and affiliated ambulatory clinics (Medical University of South Carolina and University of South Carolina or Palmetto Health) between August 2015 and November 2016. Referrals were received from physicians, respiratory therapists, nurse practitioners, and pharmacists performing inpatient medication reconciliation. After informed consent was obtained, youth and parents were instructed on how to download the SAMS app, including software for Bluetooth inhaler caps. Children and parents received a demonstration of the SAMS app and Bluetooth inhaler caps. Study personnel documented age, race, ethnicity, comorbid diagnosis, and medications based on caregiver report and provider notes. All participants were instructed to enter EMAs daily. Participants received daily SMS text message reminders to complete their 8-item EMA questionnaire. Participants did not receive reminders to take their asthma medications.

Participants returned for a final study visit including a usability survey and key informant interviews (KII) after the 2-month study period. Parents of the enrolled youth were given gift cards of US $50 at enrollment and US $150 at the final study visit to compensate for their time, travel, and any additional cell phone charges accrued during the study.

Usability Survey

The usability survey was designed based off the concepts of ease of use, and intention to use from the technology acceptability model [24]. The survey was modified from previous technology development projects and used a 5-point

Likert scale (strongly disagree to strongly agree) [25]. We also included questions regarding comfort with monitoring their disease by a smartphone based on our clinical asthma providers' early feedback that youth and families may not feel comfortable with providers knowing details on medication use.

Key Informant Interviews

Semistructured exit KII were conducted with participants (youth and parents) to better understand their experience with SAMS and how the design could be improved. Interviews were audiorecorded, transcribed, deidentified, and reviewed by our team to identify elements that could be redesigned to improve the ease of use. A more extensive qualitative analysis considering behavioral theory (eg, self-determination theory) will be reported separately.

Changes to mHealth Platform Through Iterative Design

Recruitment was suspended at the midpoint of the pilot study (ie, after enrollee #7) to implement the identified redesigned elements. The redesign included a 4-digit auto-log-in (Figure 2), individualized SMS text message reminders and offer of technical support when no EMA data were reported over any 3-day period, and SMS text message delivery at enrollment and upon request with a link to reload the app on replacement phones.

Outcomes

Medication Use and Adherence

Adherence to the controller medication (inhaled corticosteroids) regimen was calculated daily in 12-hour increments (12:00 am to 11:59 am and 12:00 pm to 11:59 pm) as the number of doses prescribed compared with the number taken over 12 hours to avoid the impact of medication overdosing and dumping [26,27]. The study group's adherence was calculated by averaging daily adherence. Duplicative data (from Bluetooth cap and manual entry) were excluded at the time of data analysis if the device subsequently paired with the smartphone and transferred data.

Assessment of Asthma Symptom Day and New Asthma Symptom Episodes

Any day with reported asthma symptoms (eg, cough, wheezing, or chest tightness) was considered an asthma symptom day for that enrollee. Asthma symptoms days reported through the EMA immediately following enrollment were considered part of an initial asthma exacerbation. To test the feasibility of using EMA to detect new or recurrent asthma symptom episodes for early intervention, we developed a definition of new asthma symptom episodes to be applied to EMA data over the 2-month study period.

New asthma symptom episodes required (1) reporting asthma symptoms a minimum of 7 days postenrollment and (2) at least one EMA reported without asthma symptoms in the interim period. A participant was permitted to have >1 new asthma symptom episode during the 2-month study period, but the events had to be separated by a report with no asthma symptoms.

Figure 2. Screenshots of an Android smartphone app for youth and caregivers, including 4-digit log-in. Image Source: Ronald J Teufel II.

Emergency Department and Hospital Visits

A statewide clinical data warehouse developed and maintained by Health Sciences South Carolina was used to collect information on asthma-related emergency department and hospital visits for study participants. The data warehouse contains over 2.7 million unique patients encountered in the inpatient, outpatient, and emergency department from 11 member institutions, including both enrollment sites for this study [28]. Visits were reported in categories of 2- and 6-month pre- and postenrollment.

Data Acquisition as Outcome

This pilot feasibility study was performed to engage participants (youth and caregivers) in the design of a mobile technology approach to facilitate frequent information exchange about inhaler use and asthma symptoms with a clinical provider. The frequency of days with data acquired on inhaler use and asthma symptoms was viewed as an indicator of both the usability by youth and their parents and feasibility.

Statistical Analysis

Our analysis included descriptive statistics for demographics, comorbid diagnosis, medications, the usability survey results, and percentage of days with asthma data acquired (EMA data or any asthma data including inhaler use or EMA). We analyzed the percent of days with data acquired before and after the app redesign using *t* test. We further investigated differences in the EMA reporting frequency by age, gender, and weekend versus weekday reporting with Pearson correlation coefficients or *t* tests. We used generalized linear mixed models with daily reports of asthma symptoms and emotional state predicting the outcome of daily adherence to controller medication accounting for the random effect of individual participants to explore whether the adherence behavior may be associated with individual EMA responses [17,23]. The models included a time variable for each study day to account for the longitudinal nature of our data with repeated measures of symptoms and EMA responses over time. This analysis enabled more accurate correlation between daily factors as it accounted for clustering on the patient level (eg, individual enrollee lower or higher adherence). Encounters for asthma in the emergency department or hospital during the 2-month study period were explored with participant-level data on reported asthma symptoms to determine whether preceding signals exist for an acute care encounter. Statistical analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC, USA, 2013).

Results

Study Population

In this study, we enrolled 14 youth aged 8-16 years and their parents (Table 2). Of the 20 patients screened for enrollment, 14 (70%) participated in this study. While 4 patients screened did not meet the inclusion criteria (age <8 years, not on a controller medication, uncertain access to cellular service because of leaving country of residence for the majority of study period, or noncompatible smartphone), 1 participant consented but medication changes immediately after consenting no longer met the inclusion criteria. Of patients who were referred and met the inclusion criteria, only 1 declined participation citing they preferred to avoid research studies. Partial EMA or adherences data were used for 3 patients because of smartphones being reported as lost or damaged.

Demographics and Clinical Characteristics

Among 14 participants, 13 were defined as high-risk asthma because of emergency department or hospital visit within past 12 months, and 1 was included because of the consideration of high risk by the primary provider. Overall, 14 patients reported comorbid diagnoses, including attention deficit hyperactive disorder (3/14), allergic rhinitis (2/14), eczema (3/14), food allergies (1/14), gastroesophageal reflux disease (1/14), obstructive sleep apnea (1/14), and vasovagal syncope (1/14). All patients were receiving both controller and rescue medications. Additional medications at the time of enrollment included antihistamines (5/14), nasal steroids (3/14), leukotriene receptor antagonists (1/14), proton-pump inhibitors or H_2 blockers (2/14), oral corticosteroids (4/14 total with 3/14 having a 3- to 5-day course of oral prednisone and 1/14 oral dexamethasone), stimulant medications (2/14), and Omalizumab (1/14). The overall controller medication adherence was 30%.

Youth and Caregiver Usability and Response to Redesign

Multimedia Appendix 2 presents usability survey responses. All youth and parents agreed or strongly agreed with the statement “I feel comfortable with a doctor or a nurse monitoring my health information using mobile technology.” During the exit interview, 1 parent stated, “I had no challenges, at all” “it was easy, and I’m not technology savvy.” Another parent highlighted the benefits of smartphone use over using computers through her statement of “...a lot of people, with the phone, they carry that everywhere. With your computer, most of the time you’ve gotta wait ‘til you get home and check it’.” Previous studies have also demonstrated African American adolescents, and their parents prefer technology interventions that are not based on a home computer platform [21]. Our iterative design process used enrollee feedback to inform the redesign of our technology-based approach for enrollees 8-14 to maximize the participant usability. Post-hoc analysis to determine the difference in the usability survey response before and after redesign was difficult because of the small cohort and frequent zero response in disagree or neutral categories. We did find the percent of enrollees who responded with agree or strongly to *the overall look and feel of the App is visually appealing* (question 3) increased nonsignificantly from 60% to 100% (*P*=.09).

Enrollees had asthma data collected, either inhaler use or EMA, on 89% of days with a significant increase when comparing enrollees before and after the redesign (86%-92%, *P*=.01). EMA data were obtained on 20% of study days for all enrollees and significantly increased after the redesign (10%-40%, *P*=.006). The redesign increased the data acquisition, and this might represent improvements in the ease of use. No significant differences were observed in the frequency of EMA reports by age (*P*=.48), gender (female 27% and male 13%, *P*=.28), or weekend versus weekday (14% and 22%, respectively, *P*=.09).

Table 2. Demographics of partcipants (N=14).

Demographics	Participants, n (%)
Age in years	
8-10	9 (64)
11-13	3 (21)
14-16	2 (14)
Gender	
Male	5 (36)
Female	9 (64)
Race	
White	0 (0)
Black	13 (93)
Other	1 (7)
Ethnicity	
Hispanic	0 (0)
Non-Hispanic	14 (100)
Insurance	
Medicaid	11 (79)
Private	1 (7)
Self-pay	2 (14)

Table 3. Clinical characteristics and medication adherence of partcipants.

Acute care visits including emergency department, hospital, or intensive care unit	Pre-enrollment (n)	Postenrollment (n)
2 months	4	1
6 months	5	3

Asthma Symptoms and Contextual Factors Impact on Adherence

EMA reports during the study period frequently included coughing (42/110, 38%), wheezing (8/111, 7%), chest tightness (9/109, 8%), stress (12/109, 11%), not relaxed (43/107, 40%), not happy (51/111, 46%), angry (11/111, 10%), and bored (57/109, 52%). In this population of high-risk youth with asthma, symptoms of wheezing or chest tightness were never reported beyond *a little* with only coughing being infrequently reported as *a lot*. Multimedia Appendix 1 provides a detailed description of responses. A total of 10 new asthma symptoms episodes were detected in the cohort over 2 months.

Our exploratory generalized linear mixed models indicated that the participants' controller medication adherence might increase on days when asthma symptoms (9.2%; 95% CI 0-18.5) or boredom were reported compared with days when reports demonstrated no asthma symptoms or boredom (Table 1). We investigated the impact of imputing missing report days as no symptom days and found a similar effect size but with a narrower CI (9.9% adherence; 95% CI 4-15). We explored this further and found the adherence was higher on days with reports of nonsymptoms than on nonreport days (35.1% vs 25.2% adherence, *P*<.001), suggesting nonreport days were similar to nonsymptom days but might represent days with even lower adherence. As nonreport days had significantly lower adherence, we excluded them from the analysis of contextual factors that impact the adherence to avoid overestimating the significance of symptoms on the adherence.

Pre- and Postenrollment Emergency Department and Hospital Visits

One patient experienced an emergency department visit while enrolled in the 2-month study compared with 4 acute care visits in the cohort 2 months pre-enrollment (Table 3). The 4 pre-enrollment acute care visits included one intensive care unit admission. In addition, 1 patient with an emergency department visit during the study period reported asthma symptoms in the days preceding the emergency department visit. During the 6 months pre-enrollment, our study cohort had 5 visits to the acute care setting, including the abovementioned intensive care unit visit compared with 3 acute care visits in the 6 months postenrollment.

Discussion

Principal Findings

Smartphone asthma monitoring was feasible and acceptable as reported by children and their families in a population of youth aged 8-16 years with high-risk asthma. The iterative design approach successfully used youth and family engagement to increase data attainment during the study period. Despite being a small-scale pilot trial, the smartphone approach resulted in high-frequency data attainment and began demonstrating statistical associations between reported asthma symptoms and emotional state and participants' daily adherence patterns. Understanding the reasons for daily adherence behavior among high-risk youth with asthma might lead to better-tailored interventions that maximize the adherence behavior. Nevertheless, larger studies should be performed to determine the generalizability of the findings.

Limitations

This feasibility trial was designed to test the acceptability and feasibility among patients, including the collection of real-time asthma data. It was not powered to find significant and generalizable differences in the adherence or other clinical outcomes. Additionally, the adherence rate (30%) reported in this trial, which was comparable to other studies, might have been artificially increased because of the Hawthorne Effect. Participants were aware of the medication monitoring and the intervention permitted patients to manually enter medication use when the Bluetooth devices ceased functioning. This approach was adopted as it was preferred by families. One parent noted their child had her inhalers at her grandparents one weekend and was away from the smartphone. Ultimately, the inhaler caps stored this information and the information was captured once in proximity to the smartphone. Thus, larger studies validating youth response to these symptom questions compared with other measures of risk, such as asthma control and emergency department use, are warranted. We cannot confirm the presence or absence of asthma symptoms reported with EMA, but previous studies suggested that this approach is valid in multiple disease states, including asthma [19,20,23]. Furthermore, individual participants may experience symptoms differently because of different body awareness, and this could impact their symptom reporting, particularly their severity of reported symptoms. More so, as a pilot study, we permitted the youth and parents to decide whether the child was to report symptoms alone or in collaboration with the parent. We used interviews to assess how the approach worked for them. Youth would frequently report symptoms alone but had discussions with their parent, which was consistent with the literature suggesting youth value a shared asthma experience with their caregiver and these ages are transitioning to the primary responsibility of asthma care. Unfortunately, we did not have an objective assessment to determine the degree of parental involvement in reporting, but this will be added to a subsequent larger study. Finally, this pilot study was conducted at 2 centers in a high-risk population; therefore, larger studies are needed to determine whether the results are generalizable to other populations.

Comparison with Prior Work

Asthma symptoms are known to vary over time because of numerous factors, including environmental exposures, medication adherence, physical exertion, and the natural progression of the disease. Mulvaney et al demonstrated that EMAs focused on asthma are associated with the established measures of asthma control (eg, Asthma Control Test) but also noted the difficulty in obtaining patient self-reported medication use [20]. Our study adds to this research by using newer technology for passive collection of medication use data, Bluetooth inhaler devices, and demonstrating an association of contextual factors, such as asthma symptoms and emotional state by EMA, with the adherence device data. The calculated adherence over days, weeks, months, and years is a series of discrete events occurring in patients' daily life that can be affected by mood and motivation. Research in other chronic diseases suggests that day-to-day factors such as control belief, mood, and social support affect daily adherence, often mediated by daily motivation [17]. Our pilot study furthers this investigation into a population of high-risk youth with asthma and suggests daily asthma symptoms and mood may impact their adherence; this suggests asthma symptoms, if recognized, may be a motivational tool for adherence in this population. Our finding associating boredom with higher adherence deserves further exploration. Boredom is typically considered a negative emotion but may also represent a time when youth are better able to adhere to medications as they are less preoccupied and distracted by other daily activities. Further studies may consider assessments of these and other momentary factors in the home environment among a larger cohort.

Ultimately, the recurrence of new asthma symptom episodes, which we observed 10 times, may be an antecedent to an emergency department or hospital visit. Although this study was not powered to determine the association of recurrent asthma symptoms and emergency department visits, it is noteworthy that our 1 patient with an emergency department visit reported recurrent asthma symptoms the day before their presentation to the acute care setting.

The recruitment process was designed to enroll high-risk patients with asthma to develop a technological tool specific to the unique needs of this population. Our participants were predominantly minority with comorbid diagnosis, insured by Medicaid, and experienced numerous acute care visits before enrollment. During KII conducted postintervention, all participants enrolled in this study indicated they had regular access to smartphones, although children who were at younger ages frequently used their parents' phones. The near-universal adoption of smartphone technology has the potential to improve access to care for high-risk children with asthma who can be difficult to reach and maintain in primary care practices.

Our technology design process included an iterative approach based on the frequent engagement pretrial and during the clinical trial's final visit. The redesign elements (eg, 4-digit automated log-in) determined by engagement were not resource-intensive but did result in a marked improvement in data accrual, supporting the importance of patient engagement when designing an mHealth platform [29-31]. The frequent rate of data accrual combined with survey and interview data consistently conveyed ease in the use of this approach. The concept of monitoring symptoms and medication use in real time in a patient's home environment could result in more timely care delivery based on current symptoms with fewer barriers to care. Ultimately, approaches to integrate technology to improve care processes for chronic disease, once monitoring is successful, are limitless. Huckvale et al noted common weaknesses in many asthma apps that should be considered in the design of future research; these include lack of consistency with best practice guidelines, ability to protect privacy, accounting for local variation in care, and demonstration of proven clinical efficacy [32,33].

Conclusions

Patients and families reported that using smartphones for real-time asthma monitoring was acceptable. The youth's daily medication adherence demonstrated a tendency to increase during days with reports of asthma symptoms or boredom. Future research should investigate other contextual factors that may impact changes in daily adherence behavior and approaches to effectively use monitoring with provider-informed interventions to improve adherence behavior and clinical outcomes.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Youth-reported asthma symptoms and emotional state with ecological momentary assessment over smartphones.

[PDF File (Adobe PDF File), 25KB - pediatrics_v1i2e8_app1.pdf]

Multimedia Appendix 2

Patients and caregiver usability assessed by postintervention survey. SAMS: Smartphone Asthma Monitoring System.

[PNG File, 190KB - pediatrics_v1i2e8_app2.png]

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Abbreviations

EMA: ecological momentary assessment
KII: key informant interview
SAMS: Smartphone Asthma Monitoring System
SMS: short message service

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Original Paper

Home to Hospital Live Streaming With Virtual Reality Goggles: A Qualitative Study Exploring the Experiences of Hospitalized Children

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Abstract

Background: Being separated from home and relatives is a major stressor for children and adolescents when hospitalized. Children long for a manner to be distracted, pleasured, and socially connected during hospitalization. Different technological devices have been applied in health care to answer those needs. Both virtual reality (VR) and videoconferencing have proven their value in hospital wards and pediatrics. VisitU combines these 2 technologies innovatively. VisitU is a recently launched VR product enabling users to be virtually at home during hospitalization.

Objective: This study aims to explore the experiences of hospitalized patients with the VR intervention of VisitU in addition to standard care.

Methods: Over a 3-month period, a purposive sample of 10 patients hospitalized in the Radboudumc Amalia Children’s Hospital was included in this qualitative study. Semistructured interviews were performed, one before and one after the use of the VR device. Patients were asked open-ended questions concerning their experiences with VisitU on practical, cognitive, emotional, and social domains. The interviews were audiorecorded and transcribed verbatim. Atlas.ti was used to support the qualitative analysis. Furthermore, the inductive thematic analysis was done according to the 6-step procedure described by Braun and Clarke.

Results: The following 6 main themes were the result of the qualitative analysis: “Being hospitalized,” “Expectations of VisitU,” “VisitU in use,” “VisitU, the benefits,” “The impact of VisitU,” and “Barriers when using VisitU.” The way VisitU was used by patients varied. The main benefits of VisitU were being somewhere else, being at home, and facilitating social connection. Limitations were experienced on the technical abilities, physical side effects, and complexity of use. Despite that, patients were positive about VisitU and unanimous in the view that they would like to use it again and advise other patients to use it.

Conclusions: This study shows the positive experiences of pediatric patients with VR live streaming. VisitU brings together the needs of patients and possibilities of VR and videoconferencing; it offers patients a way out of the hospital. Nevertheless, practical and technical obstacles must be overcome and side effects are an area of further research.

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KEYWORDS

experiences; hospitalization; mobile phone; livestream; pediatrics; qualitative analysis; videoconferencing; virtual reality

Introduction

Hospitalized children and adolescents have to cope with a complete change in their environment, people around them, and daily activities [1]. Factors found to influence their experience with hospitalization have been explored in several studies. Loneliness and boredom are 2 themes frequently mentioned [2-6]. In every age group, children reported feeling separated from home, family, and friends as one of the worst experiences during hospitalization [1,3,5,6]. Therefore, they long to communicate with peers and maintain contact with the world outside the hospital [2,4]. In addition, some patients miss appropriate toys and amusement. To oppose boredom, younger children show the desire to play and be entertained by videos or games, whereas teenagers prefer entertainment designed for their own age groups [3,5]. In search of answering those calls for connection, distraction, and pleasure in the hospital, different technological devices have been applied in health care during the last decade.

Both videoconferencing and virtual reality (VR) have been utilized to improve hospitalization and health care. Videoconferencing is defined as a live meeting of 2 or more people in separate locations being connected audiovisually through a computer or smartphone. Quantitative and qualitative studies have investigated the use of videoconferencing for hospitalized patients to keep in touch with their family, friends, or classmates [7-9]. In a qualitative study, the ability to communicate was highlighted as a primary benefit, and parents described a marked improvement of patients' mood [7]. Nicholas et al reported that the application of videophones decreased feelings of isolation and anxiety and increased feelings of connection between family members [8]. Yang et al evaluated the effect of videoconferencing during hospitalization on the reduction of stress experienced by children; their study demonstrated that the use of videoconferencing is associated with greater reduction of stress compared with those who do not use videoconferencing [9].

In addition, VR is a promising technology in health care. It is defined by the British dictionary as a computer-generated environment that closely resembles reality to the person experiencing it [10]. The virtual environment nowadays is mainly obtainable through a smartphone placed in a head-mounted display. The view to the real environment is cut off by the goggles, and patients are only able to look into the virtual world [11,12]. A considerable amount of literature has been published on the use of VR in reducing pain [13-21]. Malloy and Milling showed in a systematic review that VR distraction is an effective intervention for experimental pain and pain associated with burn injuries [14]. Especially with pediatric patients, Hua et al found a marked reduction in pain scores and heart rate when VR distraction was used in the treatment of chronic wounds [16]. Together, these studies indicated that VR is an effective distracter and a promising nonpharmacological analgesic intervention. Most studies illustrated the use of VR in outpatient settings instead of hospitalized patients [12,22,23]. However, VR in a hospital ward seems feasible and without great side effects [22-25]. A recent systematic review of VR for medical inpatients found it to be efficacious, easy to use, safe, and contributing to patient satisfaction [22]. Among oncological inpatients, studies investigating VR reported improvement of emotional state and positive emotions [12].

In the last few years, the costs of VR technology have decreased, and VR devices have become widely available and affordable. In addition to other VR devices, VisitU launched a VR technology enabling users to be virtually at home during hospitalization. The livestream connection provides patients with a 360° look around their home and a live chat with their relatives [26]. VisitU is a recent product that innovatively combines videoconferencing and VR to satisfy the need to connect with home and relatives.

As mentioned above, children report separation from family and friends as a major stressor during hospitalization. Therefore, VisitU is worth being investigated. This would be the first study that focuses on VR live streaming, the combination of videoconferencing and VR in one device. The objective of this study is to investigate the experience with VisitU among hospitalized children and adolescents. To explore the first experiences with VisitU, a qualitative approach was chosen.

Methods

Setting and Sample

Over a 3-month period (June-August 2017), eligible patients in the Radboudumc Amalia Children's Hospital (Nijmegen, the Netherlands) were included in this qualitative study. Children were aged 6-18 years and hospitalized on the medium care unit for at least 4 days. Children with an increased risk of seizures, severe visual impairment or blindness, reduced consciousness, severe mental retardation, or non-Dutch-speaking were excluded [27]. A purposive sample of patients was recruited to achieve a range in age, gender, hospital to home distance, and "hospital experience." One after another, patients were selected from the eligible children. Data saturation and research period determined the sample size. Data saturation was reached when no new topics were discussed during the interviews. This study was approved by the Research Ethics Committee of the Radboud University Nijmegen Medical Centre. The study did not fall within the remit of the Medical Research Involving Human Subjects Act (WMO).

Figure 1. VisitU home to hospital livestream.

Intervention

VisitU includes an Asus Zen Book UX305 with video card and video live streaming software, a 360° Theta S camera and a Samsung Galaxy S6 combined with Samsung GearVR goggles (Figure 1). Moreover, several free available VR apps especially designed for VR goggles were installed. Patients were free to use them next to the livestream. Patients received VisitU for 3-5 days during their hospitalization. Before the start of the experiment, the researcher (AB) briefly instructed the patients on the use of VisitU. Furthermore, written instructions were available on paper and online. In practice, patients utilized the Samsung Galaxy S6 and the Samsung VR goggles in the hospital, and parents used the laptop and 360° camera at home. When the camera was connected to the laptop, a virtual meeting could be created. Subsequently, an email invitation was sent to the smartphone, and by accepting the invitation, the live VR meeting would start automatically. The smartphone was then placed in the VR goggles, and patients could experience the virtual visit to their home. During the research period, VisitU updated their service and thereafter, the VR livestream opened directly through an app, and accepting the email invitation was no longer necessary.

Data Collection

Data collection started with including patients who, in consultation with the pedagogical staff, were approached by the researcher. One patient at a time was included because only one VR device was available for research. Informed written consent was obtained from all subjects. Subsequently, 2 semistructured interviews were conducted—one before and one after the period in which the device could be used. The qualitative data were collected by audiorecording the interviews. In addition, patients or their parents were asked to keep a diary on the use of the VR intervention. With regard to the interview, a semistructured interview guide was developed concerning the background information, experiences with VisitU in different domains, and relevant factors found in the literature on VR and videoconferencing (Multimedia Appendix 1). The interview guide was discussed among the research team and evaluated after every couple of interviews. The interviews were conducted by the researcher (AB) and preferably performed face-to-face in the hospital ward. We interviewed patients, parents, or other relatives. The duration and content of the interviews were adjusted to the age, sickness, and concentration of each patient. Consequently, in total, 15-25 minutes of interview data for each patient were recorded. Furthermore, verbal member check was performed at the end of every second interview.

Data Analysis

The interviews were transcribed verbatim using audio transcription software F4 [28]. In addition, ATLAS.ti software was used to facilitate the analysis of the interviews [29]. The inductive thematic analysis was done according to the 6-step procedure described by Braun and Clarke [30] and it proceeded as follows. We started with familiarizing ourselves with the data by transcribing and rereading the interviews. Then, the process of open coding was performed, followed by revising the codes, also known as axial coding. To continue the inductive analysis, the open codes were grouped into categories. The categories were discussed among the research team and were subsequently collected in themes. The interim analysis was conducted to refine interview questions and estimate data saturation [31]. Of note, the data collected by the diary were not separately analyzed. The information obtained from the diary (ie, time of use and profits and barriers of the VR device) was used during the interviews.

Results

Study Group

A total of 10 children were included, and 18 interviews were performed in this study. With 1 child, based on medical conditions, we chose to perform only one interview after the use of VisitU. Another patient was lost to follow-up; therefore, the second interview could not take place. Of 18 interviews, 3 were with patients exclusively, 13 with both the patient and the parent, and 2 with a parent or relative only. The method of interviewing was face-to-face 15 times and in 3 cases, by telephone because of early or weekend discharge. All patients aged 9-15 years old (mean age: 11 years and 8 months); 8 boys and 2 girls were included. The time of hospitalization was 5 days to >4 weeks (median 12 days), and the average hospital to home distance was 55 km (range 3-100 km). Of 10 patients, 3 were treated in isolation during hospitalization. The specialty of care varied (surgery, neurology, pulmonology, oncology, infectious disease, and cardiology), and the number of hospitalizations ranged from 1 to 3 over the last year.

Overview

The interviews were transcribed with a total of 27,531 words from which 79 codes were made. After interviewing 8 children, no new codes came up from the interviews. After analysis, the codes were subdivided into 18 categories and collected into 6 themes as follows: “Being hospitalized,” “Expectations of VisitU,” “VisitU in use,” “VisitU, the profits,” “The impact of VisitU,” and “Barriers when using VisitU.” The first 2 themes represent the patients’ view and experiences before the use of VisitU, and the last 4 themes represent the experiences with VisitU after usage. Table 1 shows an overview of the themes and categories with corresponding quotes.

Being Hospitalized

The impact hospitalization, ways of coping, and social connection were discussed. A majority of the patients (7/10) stated they did not want to be hospitalized. A variety of reasons were expressed such as physical discomfort, boredom, and uncertainty. Moreover, being obliged to lay in bed, to stay in the hospital, and to take drugs was bothersome. The wish for the presence of friends and family around them was expressed by half of the patients. The absence of their pets was additionally named by 2 patients. The children longed for participating in their usual activities, such as going to school, going on a vacation trip, or simply being at home. To deal with their hospitalization, different methods of distraction were used such as gaming or drawing. To connect with friends or other relatives, patients received visits in the hospital or were digitally in contact by texting or video calling. Contacts with the hospital staff and sources of entertainment, such as electronics, were mentioned as positive aspects of hospitalization.

Expectations of VisitU

Along with discussing expectations of VisitU, patients were questioned about previous experiences with VR. Opinions differed as to whether the use of VR earlier has been a satisfying experience. Although a minority of the patients (4/10) had previously used a VR device, all had an idea of the purpose and utilization of VR goggles; their expectations varied. Some patients expected to look around at home or in a virtual world, whereas they were not really there. Other expectations were the 360° look around in, the 3D effect of the VR goggles or “just something new.”

VisitU in Use

There was a range in time, location, person, and content concerning the actual use of the VR system. The usage of the VR goggles differed from once to multiple times a day. The duration ranged from 1 minute to multiple hours, and the median duration was 15 minutes each time. The laptop and camera were most often brought home, set up by one of the parents, and installed at one usual place. In the hospital, both patients and their friends and other relatives used the VR goggles. When using the VR livestream, patients talked with relatives at home, observed their daily activities, or gazed around in the house. In practice, 7 of 10 patients used the VR livestream, and 6 of them utilized other VR apps. One patient did not use the VisitU device at all; instead, 2D livestream was used. In the case of using other VR apps, patients played with free available VR apps, such as a rollercoaster app, or watched VR videos on YouTube.

VisitU: The Benefits

The main benefit, according to almost all patients, was the ability to be somewhere else through the VR goggles. The view of the hospital surroundings was blocked through the head-mounted display, and patients said they were, therefore, “not being here but there.” As a result, patients were offered a way to escape the hospital. Not only being somewhere else was mentioned as a benefit but also, in particular, the opportunity to virtually be in their own houses (5/6). In addition, VisitU facilitated social connection with relatives at home. Children could easily talk to their parents, siblings, or friends and be part of their “normal lives.” The distraction VR created was another benefit that 3 of 8 patients and relatives reported. It was just something different than the hospital, and patients enjoyed playing with the VR device.

The Impact of Using VisitU

When talking about their thoughts on VR livestream, all patients’ reactions were positive. There was a range in enthusiasm from “I thought it was quite nice” to “Very enjoyable and cool!” When asked, patients were unanimous in the view that they would like to use VisitU again and would recommend it to other patients. Patients said that VisitU made them feel happy; for example, one mother said, “As soon as he puts on the VR goggles, a big smile appears on his face.” Noteworthy is the comment of one patient that he felt “depressed” right after the usage because he did not want to quit. Some parents and patients said they also used alternative technical devices like WhatsApp or video calling to fulfill their needs for connection. For another patient, the VR games did not meet his expectations. Part of experiencing VR is the perception of being physically present in the virtual world. All patients said the virtual world felt real to them in some way. The presence of the virtual world was surprising for one patient; she described it as “First, I could see my parents and the next moment, when taking the VR goggles off, I was back in the hospital.” The sounds of the hospital and the impossibility to touch their relatives at home were mentioned to decrease the sense of reality.

Table 1. The qualitative analysis.

Theme and category	Quote (example)[a]
Being hospitalized	
Impact of hospitalization	Interviewer: What's it like to be in the hospital? 8aChildB09: I don't like it. Actually, I don't want to be here.
Social connection during hospitalization	9aChildB15: I would rather be at home, because there I can be among all my friends and everything. I can't do that so much here.
Coping with hospitalization	4aChildB11: Yes, you can play and sometimes people come and play with you.
VisitU in use	
Ways of use VisitU	5bChildB09: The whole evening really, I used it quite a lot.
Using other VR[b] apps	1bChildB14:...the extra apps on it were also quite fun to use…at one point I could see the T. rex eat from, I didn't see what really, but I could literally stand below them while they were eating.
VisitU: the benefits	
Being somewhere else	2bChildB14: Just to be in a different place...So, you're away from the hospital.
Being home	9bChildB15:...so you also get a sense of knowing what it looks like at home and what has changed and everything.
Being connected	1bChildB14: I saw our pets again for a little while; it was nice to see them again for a moment. I do see them every now and again with WhatsApp, but then [with VR glasses] I saw them better...at one point she [dog] also looked and pushed her little nose up against the camera so I was able to see her again.
Being distracted	10bChildG14: It does help to take your mind off being in the hospital a little bit.
Barriers when using VisitU	
Technical reliability	5bChildB09: So, I mean, the patient can, for example, only see the parents. If the parents could also see the child, it would be a bit better, but that will be difficult to create, I think.
Complexity	5bMotherB09: I installed it at home [laughs]...I thought it was still quite complicated, as you obviously have to create a moment every time.
Physical effects	3bChildB10: But after having played with these goggles a lot, my head hurts. I don't feel dizzy; my head just hurts.
Impact of using VisitU	
Reality of VR	10bChildG14: Yes, home is different, because it's just a bit different really…so grandma has a glass door and often you can see yourself in it, but when I turned around in it, when I turned toward it [with VR goggles], I didn't see myself [in the glass].
Feelings on VisitU	9bChildB15**:** Then it´s less hard to be here in the hospital.
Thoughts on VisitU	7bSister13B09: Yeah I do think I would recommend it...

[a] Codes used for quotation consist of the number of a patient, a letter "a" for first and "b" for second interview, the role of the quoted person, gender, and age; for example, 3bChildB10 is the 3rd child, second interview (b), patient himself, boy (B) and 10 years old.

[b] VR: virtual reality.

Barriers When Using VisitU

Although most patients were enthusiastic about the idea of VisitU, some of them experienced technical, practical, or physical limitations. The one-way connection of the VR livestream was seen as a disadvantage by half of the parents or patients. At home, they could only hear the patient in contrast to the patient who could also see the other people. On the quality of the resolution of the VR goggles, opinions differed, and an upgrade of the display resolution was suggested. The high temperature of the telephone when using the VR goggles was also noticed by one patient. Besides these disadvantages, 2 parents had to deal with temporary technical problems as a result of an outdated version of VisitU and a problem with the camera software. The unfamiliarity with VR and the system was brought up as a barrier, and 3 of 6 parents thought that the installation was complex and time consuming. Patients, in contrast to their parents, thought the smartphone and VR goggles were easy to use. More than half of the patients (5/8) experienced physical side effects when using VR for a while. Symptoms were experienced after a range of only 1 minute to half an hour of use. Patients mentioned side effects such as a headache, nausea, and dizziness; these symptoms disappeared when the VR livestream was interrupted. Subsequently, most patients continued the use of VisitU despite experiencing symptoms.

Challenges for the Hospital Staff

Concerning the technical reliability during the research period, 2 software problems were noticed. The first problem was the need of a software update, and the second problem relating to the camera and teleporting system occurred. On the other hand, the organization was a challenge for the researchers. Scheduling a meeting with each patient to hand over VisitU was difficult as a consequence of unplanned care in a hospital ward.

Discussion

Principal Findings

This study shows that pediatric inpatients were positive about the idea, effect, and possibilities of VR live streaming. Barriers were experienced on the technical abilities, physical side effects, and complexity of usage. In addition, the research shows that hospitalized children long for participation in their usual activities, social connection, and distraction. Being somewhere else, being at home, and facilitating social connection were the main benefits of VisitU. Therefore, VisitU matches the needs of these hospitalized patients. Although the way of use by patients varied, all patients would recommend VisitU and would use it again. Figure 2 presents a hypothesized model of the experiences with VR livestream based on these results. We assume that both the expectations and needs, as well as the experienced barriers and benefits, affect the degree of satisfaction of the product and consequently, affect the usage and impact of VR livestream.

Comparison With Prior Work

As far as we know, this is the first study that focuses on VR livestream. Therefore, the results are unique and cannot be compared directly to previous literature. Therefore, in this section, the findings will be compared with the literature on either videoconferencing or VR separately. The observations in this study support the hypothesis that combining those 2 techniques in one device is valuable for hospitalized patients. Prior studies about videoconferencing and VR have noted similar effects as our study regarding the feelings and thoughts of users [7-9,12]. Patients felt more positive and felt more "normal" when they used videoconferencing [7,8]. In addition, VR improved the emotional state and positive emotions during hospitalization [12]. Therefore, it is likely that the combination of VR and videoconferencing, as the results of this study suggest, also causes positive feelings and improves the experience of hospitalization.

Regarding the main benefits of VisitU, the finding that live streaming facilitates social connection agrees with the findings of Nicholas et al's findings evaluating videophone communication; their study showed that patients felt less lonely, frightened, and stressed when talking with family and friends on the videophone [8]. In addition, in a feasibility study of VR in the hospital, being somewhere else was also found to be a benefit. Here confirming our findings, a patient described VR provides an "escape" from the confines and boredom of the hospital room [23].

Little is known about using VR interventions unrestricted in a hospital setting, like VisitU was used. In nearly all studies about videoconferencing and VR, the actual use was either one-time or regulated. Only a few studies reported the efficacy of repeatedly using VR. Our results are in line with their suggestions that VR stays effective after repeatedly using it within a couple of days [20,32].

Figure 2. Model of experiences with VR livestream.

The presence of technical and practical barriers mentioned by patients in this study seems to be consistent with previous research on electronic health (eHealth) and VR [33,34]. Technical reliability is one of the main challenges when implementing an eHealth program [33]. Along with the technical problems, Eysenbach hypothesized that usability, ease of enrollment, workload, and time required are other factors obviously affecting the usage of eHealth [35]. These themes are comparable to the factors mentioned in this study. The side effects match those observed in former VR studies. More than half of the patients reported side effects. In a recent systematic review of VR for hospitalized patients, only 17% of patients experienced side effects. In contrast, another study reported symptoms in 80% of VR users [12,22,36]. No clear cause exists for this variety in the frequency of side effects. Cyber sickness is known to be a result of accumulating factors, including the duration of exposure to VR. Therefore, unrestricted use may be the reason a majority of patients experienced side effects [37]. In addition, as a consequence of being hospitalized for a longer period, this specific population could be more sensitive to side effects. Furthermore, technical adjustments to VR devices can reduce symptoms of cyber sickness [36]. Hopefully, these techniques will decrease the number of side effects in the near future [36].

Strengths and Limitations

The setting and design are the key strengths of this study. An explorative qualitative approach and inductive analysis were chosen as design to focus on the patients’ perspectives and understand why and if VisitU would be a useful innovation. In addition, the setting was a tertiary hospital with patients hospitalized for mostly a longer period and a relatively far distance from home. Therefore, VisitU was relevant for this specific population.

Despite the strengths, this study also has several limitations. The major limitation of this study is the risk for the researcher bias because the process of coding was only done by one researcher (AB). To overcome this limitation, the codes and analysis were discussed on a regular basis among the research team (LJ and CN) [38]. To ensure external reliability, the raw data, transcribed interviews, and codes are well documented and transparent [39]. The method of triangulation using a diary was barely used by patients. To overcome this limitation, the information was asked in the interviews. Finally, a purposive sample was chosen to improve the external validity; unfortunately, the boy-to-girl ratio is unequal, and it is not known if this affects the results [39].

Recommendations

Although this study is based on a small sample of participants, the findings suggest VisitU brings together the needs of patients and the possibilities of VR and videoconferencing. VisitU seems to be feasible in hospital wards, and we recommend the implementation together with further development and evaluation. Further work is required to improve the reliability of the VisitU technology and the usability of the system. Along with developing VisitU, more research is needed on VR live streaming in other pediatric populations and on different implications of VisitU, such as intensive care units or isolation rooms. Furthermore, further research is required to reduce the side effects of VR. Children do not like being hospitalized; therefore, other innovative ways to improve the experiences with hospitalization are also a field of further research.

Conclusions

This study shows the positive experiences of children and adolescents with VR live streaming. The results suggest that VR can improve the experiences with hospitalization in pediatric patients. VisitU offers patients a way out of the hospital. It meets the needs of patients for being at home, socially connected, and distracted during hospitalization. Nevertheless, technical and practical barriers must be overcome, and further studies must be performed to understand the side effects of VR.

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Authors' Contributions

AB worked as a medical intern and was trained in qualitative analysis and interviewing. LJ worked as a pediatric resident and CJ works as professor in pediatrics at the Radboudumc Amalia Children’s Hospital. All authors participated in the design of the study and contributed to the analysis and interpretation of the data. AB held, transcribed, and coded interviews, as well as drafted the manuscript. CN and LJ critically reviewed the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Interview guide.
[PDF File (Adobe PDF File), 29KB - pediatrics_v1i2e10_app1.pdf]

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Abbreviations

eHealth: electronic health
VR: virtual reality

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Original Paper

Mobile Phone Access and Willingness Among Mothers to Receive a Text-Based mHealth Intervention to Improve Prenatal Care in Northwest Ethiopia: Cross-Sectional Study

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Abstract

Background: Maternal mortality remains high in many low- and middle-income countries where limited access to health services is linked to low antenatal care utilization. Effective communication and engagement with care providers are vital for the delivery and receipt of sufficient health care services. There is strong evidence that simple text-based interventions can improve the prenatal care utilization, but most mobile health (mHealth) interventions are not implemented on a larger scale owing to the lack of context and preliminary evidence on how to make the transition.

Objective: The objective of this study was to determine access to mobile phones by pregnant women attending antenatal care as well as willingness to receive a text message (short message service, SMS)–based mHealth intervention for antenatal care services and identify its associated factors among pregnant women attending an antenatal care clinic in Gondar Town Administration, Northwest Ethiopia, Africa.

Methods: A cross-sectional quantitative study was conducted among 422 pregnant women attending antenatal care from March 27 to April 28, 2017. Data were collected using structured questionnaires. Data entry and analysis were performed using Epi-Info version 7 and SPSS version 20, respectively. In addition, descriptive statistics and bivariable and multivariable logistic regression analyses were performed. Furthermore, odds ratio with 95% CI was used to identify factors associated with the willingness to receive a text message–based mHealth intervention.

Results: A total of 416 respondents (response rate 98.6%, 416/422) were included in the analysis. About 76.7% (319/416) of respondents owned a mobile phone and 71.2% (296/416) were willing to receive an SMS text message. Among the mobile phone owners, only 37.6% (120/319) were having smartphones. Of all women with mobile phones, 89.7% (286/319) described that they are the primary holders of these phones and among them, 85.0% (271/319) reported having had the same phone number for more than a year. Among the phone owners, 90.0% (287/319) described that they could read and 86.8% (277/416) could send SMS text messages using their mobile phones in their day-to-day activities. Among pregnant women who were willing to receive SMS text messages, about 96.3% (285/296) were willing to receive information regarding activities or things to avoid during pregnancy. Factors associated with willingness were youth age group (adjusted odds ratio [AOR] 2.869, 95% CI 1.451-5.651), having attained secondary and higher educational level (AOR 4.995, 95% CI 1.489-14.773), and the frequency of mobile phone use (AOR 0.319, 95% CI 0.141-0.718).

Conclusions: A high proportion of pregnant women in an antenatal care clinic in this remote setting have a mobile phone and are willing to receive an SMS text message–based mHealth intervention. Age, educational status, and the frequency of mobile phone use are significantly associated with the willingness to receive SMS text message–based mHealth interventions.

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KEYWORDS

mHealth; mobile phone; pregnant women; SMS; willingness; Ethiopia; antenatal care; maternal health

Introduction

Maternal health is a critical issue to be addressed worldwide. Every minute of every day, somewhere in the world, women lose their lives because of complications related to pregnancy and childbirth. It is estimated that globally every day about 830 women die from preventable causes related to pregnancy and delivery, and about 99% of all maternal deaths occur in developing countries where access to antenatal care (ANC) services is limited [1]. A majority of these deaths are preventable through focused ANC service [2,3]. It has been widely stated that routine ANC visit is one of the most effective ways to reduce maternal morbidity and mortality [4]. Sub-Saharan Africa is the region with a high maternal mortality ratio and low ANC utilization [3].

According to the Ethiopian Demographic and Health survey 2016 key indicators report, maternal mortality ratio in Ethiopia is 412/100,000 [5]. Despite calls by the World Health Organization for a minimum of 4 ANC visits, only 32% of pregnant women in Ethiopia attend the recommended ANC service, with residential variations [5]. Urban women were more likely than rural women to have received ANC from a skilled provider. Among different barriers, limited access to health services and lack of effective communication are among the major barriers for low ANC [6]. A missed appointment is a major cause of inefficiency in health care delivery, with substantial financial costs for the health system, leading to delays in the diagnosis and appropriate treatment [7]. In addition, effective communication is vital for the delivery and receipt of sufficient health care services [8,9]. Hence, new and innovative strategies are required to overcome the problem and improve ANC services. The use of mobile telecommunication technology at medical and public health practice is gaining attention because it gives the chances to rapidly connect people, reducing delay across the chain of health decisions, and positively affecting the lives of many in the underserved population [10,11].

Mobile phones are increasingly used in health care systems in low- and middle-income countries and are considered as innovative solutions that have immense potential to overcome barriers of access to ANC service [12,13]. Several scientific papers have shown that short message service (SMS) text messaging-based mobile health (mHealth) intervention could potentially improve maternal and child health [13-18]. SMS-based mHealth messaging plays an important role in maternal health care like reminders for health care appointments [19].

In Ethiopia, mobile subscribers are increasing exponentially and the mobile network coverage is expanding [20]. Even though there is only one government-owned telecom company that provides the service, the use of phone call and SMS text messaging is expectantly increasing among health care workers in day-to-day health service provisions. There is a great opportunity to link the constantly growing mobile telecommunication technology with the many-sided maternal and child health care programs and strategies. Mobile phone ownership among pregnant women attending ANC and the willingness of women to receive SMS text messages remain unknown in the Ethiopian context. Before implementing the SMS text message–based mHealth intervention, it is essential to know the level of access to mobile phone and the willingness of women to receive SMS text message–based interventions.

Therefore, the objectives of this study are as follows:

- To assess the access to mobile phone among pregnant women attending ANC clinics in Gondar Town Administration
- To determine the willingness of those women to receive SMS text message–based mHealth interventions
- To identify the factors associated with the willingness to receive SMS text message–based mHealth interventions among pregnant women attending ANC

Methods

Study Design and Setting

A cross-sectional quantitative study was conducted at 8 health facilities from March 27 to April 28, 2017, in the Gondar Town Administration, Northwest Ethiopia. The Gondar Town Administration is divided into 8 clusters namely Gondar, Ginbot 20, Azezo, Gebriel, Maraki, Woleka, Teda, and Belajig; the administration has a total of 24 Kebele (13 urban and 11 rural). In addition, the administration has a total of 23 public health facilities, 1 referral hospital, 8 health centers, and 14 health posts. Of the estimated population of the town, 49.5% (162,192/327,661) are females and 50.5% (165,469/327,661) are males. Among the total population, 260,183 are urban inhabitants and the rest 67,478 are rural inhabitants. In the 2016-17 budget year, the number of women in the reproductive age group was 77,262 and the estimated number of pregnancies was 11,042 (data from Gondar Town health department). In the Ethiopian context, health center means a health facility that provides primary health care and urban area implies a town that consists of at least 2000 residences.

Study Subjects

All women who were pregnant and attending ANC service at health centers during the study period were used as the study population.

Sample Size

The sample size of this study was determined using the single population proportion formula ($n=(z\ \alpha/2)^2pq/\partial^2$) with the following assumptions:

> n=the required sample size; z=the value of the standard normal distribution corresponding to $\alpha/2=1.96$; p=the proportion of pregnant women who are attending ANC and willing to be contacted by mobile phone; $q=1-p$, the proportion of pregnant women who are attending ANC and not willing to be contacted by mobile phone; and ∂= margin of error 5% (0.05).

We could not find any studies conducted to determine the mobile phone ownership among pregnant women attending ANC in Ethiopia, although the general subscriber identity module (SIM or subscriber identification module) population in Ethiopia is 48.3% [20]. Moreover, we could not find any study conducted in Ethiopia to determine the willingness of pregnant women who are attending ANC to receive SMS text message–based mHealth interventions for ANC services. Therefore, we assumed that 50% of pregnant women are willing to receive an SMS text message–based mHealth intervention for ANC services. The maximum sample size was 384 using the proportion of pregnant women who were attending ANC and willing to be contacted by mobile phone. Considering a 10% nonresponse rate, we calculated the final sample size to be 422. Thus, a systematic random sampling technique was performed to select 422 study participants.

Data Collection Tools and Procedure

Women exiting ANC visit were approached for interviews at each of the 8 health centers. The interviews included sociodemographic characteristics, physical accessibility to a health care facility, electricity and network availability, patterns of mobile phone use, and women’s opinion and willingness to receive health information via SMS text messages through mobile phones. Questionnaires were first developed in English, which then underwent forward and backward translation to ensure semantic consistency (English to Amharic then English), for the appropriateness and easiness in approaching study participants. Of note, a pretest of the questionnaire was conducted among pregnant women attending ANC (5% of the sample) before the study period at health centers in the Debre-tabor Town Administration, following which necessary modifications were made on the basis of pretest findings. Research personnel, including 2 health information technicians, 2 nurses with bachelor degrees acting as supervisors, and 8 clinical nurses serving as data collectors or interviewers, received a 1-day training course on implementing the evaluation, which included training on research ethics, providing informed consent, data collection procedures, data collecting tools, how to approach participants, data confidentiality, respondents’ right and all the study protocols to be followed throughout the course of the data collection period. In addition, continuous monitoring by supervisors was done throughout the data collection period to ensure that the data were collected according to the study protocol. The completed questionnaires were stored in binders in nurses’ class until collected by the principal investigator.

Data Management and Statistical Analysis

Data were entered using Epi-Info version 7 and transferred to SPSS version 20. Descriptive statistics were performed to describe the study population. We used the binary logistic regression to analyze the association of each study variable on the outcome variable. The dependent variable was designated as “no”=0 (have no willingness) and “yes”=1 (for having willingness). Variables significantly associated with the outcome variable ($P<.2$) in the bivariable analysis were included in the multivariable logistic regression analysis for controlling the possible effects of confounders. In the multivariable analysis, Hosmer and Lemeshow goodness-of-fit test was performed ($P=.76$), and variables which were significant based on the adjusted odds ratio (AOR), with 95% CI and $P<.05$, were considered to be the determinant factors of willingness to receive an SMS text message–based mHealth intervention.

Ethical Consideration

Ethical clearance was obtained from the ethical review board of the University of Gondar. In addition, oral consent was obtained from study participants after narrating the objective of the study; they were also informed about the benefits of the study. If they felt discomfort during the interview, they were informed that they could stop at any time. Moreover, confidentiality assurance was provided to study participants on any information provided by them; the data collection procedure was anonymous, and their privacy was upheld.

Results

Mobile Phone Ownership

A total of 422 pregnant women from 8 public health centers were approached; of them, 416 responded to complete all the questionnaires at each health center (response rate 98.6%). Of all respondents, 81.3% (338/416) were urban residents. The age of respondents ranged from 18 to 45 years (mean age 26.6 [SD 5.4] years). In addition, 94.5% (393/416) of them were married, 67.3% (280/416) were housewives, and 51.7% (215/416) had attained at least secondary educational level (Table 1).

Table 1 shows that 76.7% (319/416) pregnant women owned a mobile phone; of them, 63.0% (201/319) were in the age group of ≥25 years. Almost all mobile phone owners were married (303/319, 95.0%) and 63.0% (201/319) had attained secondary and higher educational level.

Patterns of Mobile Phone Use

In this study, 97 pregnant women had no mobile phone; main reasons reported for not owning a mobile phone currently were cannot afford to buy (53/97, 54.6%), followed by mobile phone broken (17/97, 17.5%).

Of all women with mobile phones, 89.7% (286/319) described that they are the primary holders of these phones; however, 29.8% (94/319) of them described that they share their mobile phone with others, especially with other family members. In addition, 51.4% (164/319) of them locked their mobile phone with a password and 30.1% (96/319) put their mobile phone in a place where others can see and access it easily. Furthermore, 31.3% (100/319) of women reported that there were times or places where they did not answer calls and 14.7% (47/319) reported switching-off mobile phones during the daytime.

Of the respondents with mobile phones, 85.0% (271/319) reported having had the same phone number for more than a year; the other 15.0% (48/319) reported changing their mobile phone number in the last 1 year. In addition, 37.6% (120/319) of current mobile phone owners had smartphones. Among current mobile phone owners, 47.3% (151/319) of pregnant women described that they accessed the internet through their mobile phones, which could be either a basic phone or smartphone; of them, 94.7% (143/151) reported using the Facebook app mainly to stay in touch with friends and relatives through this social media platform.

Table 1. Sociodemographic characteristics of pregnant women attending antenatal care follow-up at health centers in the Gondar Town Administration, Northwest Ethiopia, 2017.

Sociodemographic characteristics	Pregnant women (n=416), n (%)	Pregnant women owning a mobile phone (n=319), n (%)
Age		
15-24	160 (38.5)	118 (37.0)
≥25	256 (61.5)	201 (63.0)
Residence		
Urban	338 (81.3)	298 (93.4)
Rural	78 (18.7)	21 (26.6)
Marital status		
Not married	14 (3.4)	10 (3.1)
Married	393 (94.5)	303 (95)
Other[a]	9 (2.2)	6 (1.9)
Educational status		
Cannot read and write	70 (21.9)	21 (6.6)
Informal education	21 (5.0)	12 (3.8)
Primary	110 (26.4)	85 (26.6)
Secondary and above	215 (51.7)	201 (63.0)
Occupation		
Housewife	280 (67.3)	192 (60.2)
Civil servant	49 (11.8)	49 (15.4)
Merchant	48 (11.5)	46 (14.4)
Daily laborer	24 (5.8)	20 (6.3)
Student	12 (2.9)	10 (3.1)
Other[b]	3 (0.7)	2 (0.6)
Who do you live with		
Family	385 (92.5)	294 (92.2)
Alone	24 (5.8)	21 (6.6)
Parents	7 (1.7)	4 (1.3)
Number of children		
No child	185 (44.5)	160 (50.2)
1	77 (18.5)	59 (18.5)
2	80 (19.2)	60 (18.8)
3	44 (10.6)	29 (9.1)
≥4	30 (7.2)	11 (3.4)

[a] Separated, windowed, and died.

[b] Farmer, driver, and jobless.

Of all respondents with mobile phones, 90.0% (287/319) described that they could read and 86.8% (277/416) could send SMS text messages using their mobile phones. However, 6.3% (18/319) of them described that they deleted SMS text messages without reading them. Among those who currently owned a mobile phone, only 33.2% (106/319) used their mobile phone for health-related information or purposes; of them, 50.0% (53/106) respondents used to set the alarm to take medication, 36.9% (39/106) received health-related SMS text messages or calls from health organization or health care providers, 32.1% (34/106) used their phones to consult health professionals, and 24.5% (26/106) used their phones to browse health-related information using the internet.

Willingness to Receive a Short Message Service Text Message–Based mHealth Intervention

As shown in Table 2, those who owned smartphones were more willing to receive SMS text messages than those who owned standard feature phones (101, 84.2% vs 144, 72.4%). Respondents who had used mobile phones to send SMS text messages were also more willing to receive SMS text message–based health interventions compared with those who never used the SMS text messaging service before (80.3% vs 67.8%).

Respondents who used their phones as an alarm reminder to take their medication were more willing to receive SMS text message–based mHealth interventions than those who did not (85% vs 75.2%). This willingness was also observed in respondents who received SMS text messages from health organization before compared with those who had not (79.5% vs 76.4%). The frequency of the mobile phone use also correlated with the willingness to accept an SMS text message–based mHealth intervention. Of note, 229 women (80.1%) who “always” used their mobile phones were willing to receive SMS text messages compared with those who only used their mobile phones “sometimes” 16 (48.5%). The willingness to receive SMS text messages was higher among respondents who locked their mobile phone with a password than those who did not lock their mobile phone with a password (80.5% vs 72.9%). In addition, internet users via their mobile phone were also more willing than noninternet users (82.1% vs 72%).

Attitude and Willingness to Receive Short Message Service Text Message–Based mHealth Interventions

In this study, 71.2% (296/416) respondents were willing to receive SMS text messages with information regarding ANC (Table 3). The pregnancy period at which they would want to begin receiving SMS text messages varied greatly: from 1 month, 117/296, 39.5%; from 3 months, 163/296, 55.1%; and from 6 months, 10/296, 3.4%, and at 9 months of pregnancy but before delivery 2% (6/296).

The time of day at which they would want to receive SMS text messages varied greatly. Overall, 19.9% (59/296) of women preferred receiving an SMS text message at morning only (8 am-before 12 pm), 6.8% (20/296) in the afternoon only (12 pm-before 4 pm), 12.8% (38/296) in the evening only (4 pm-before 8 pm), whereas 60.5% (179/296) described they could receive the SMS text messages at any time of the day. Among respondents who were willing to receive SMS text messages, more than three-fourth preferred receiving them at a frequency of once a week.

Overall, women were interested in receiving pregnancy and related information via SMS text messages. Among pregnant women who were willing to receive SMS text messages, about 96.3% (285/296) were willing to receive information regarding activities or things to avoid during pregnancy.

Those who intended to receive health information regarding delivery courses via SMS text messages were 90.5% (268/296). In addition, respondents were willing to receive SMS text messages about what to expect at various stages of pregnancy (249/296, 84.1%), prenatal dietary information (236/296, 79.7%), appointment reminders (209/296, 70.6%), when to call a doctor during pregnancy (107/296, 36.1%), and physical activities during pregnancy (88/296, 29.7%). Among respondents who were willing to receive SMS text messages, 78.4% (232/296) indicated that they were willing to pay for the service based on the current SMS text messaging rates.

Factors Associated With the Willingness to Receive Short Message Service Text Messages

Variables in the bivariable analysis of sociodemographics, patterns of mobile phone use, access to a health facility, and ANC-related factors around the willingness to receive SMS text messages that had $P<.20$ were further considered in the multivariable analysis (Table 4). The multivariable logistic regression analysis revealed that the following factors were significantly associated with the willingness to receive SMS text message–based mHealth intervention among pregnant women: youth age group (15-24 years, $P=.002$); educational status (primary: $P=.05$; secondary and above: $P=.004$); and mobile phone use as “always” ($P=.006$; Table 4). Respondents in the youth age group were 2.87 times (AOR 2.869, 95% CI 1.451-5.651) more likely willing to receive SMS text message–based mHealth interventions than those aged >25 years. Respondents with secondary and higher educational level were 5 times (AOR 4.995, 95% CI 1.689-14.773) more willing to receive SMS text messages than those with educational level below secondary. Respondents who used a mobile phone “sometimes” were 68.1% (AOR 0.319, 95% CI 0.141-0.718) less likely to be willing than those who used mobile phone always.

Table 2. Willingness to receive the short message service (SMS) text message–based mHealth intervention by patterns of mobile phone use among pregnant women attending antenatal care follow-up at health centers in the Gondar Town Administration, Northwest Ethiopia, 2017 (N=319).

Mobile phone use patterns	Total, n (%)	Willingness to receive SMS text messages, n (%)	
		Yes	No
Mobile phone type			
Smart	120 (37.6)	101 (84.2)	19 (15.8)
Standard	199 (62.4)	144 (72.4)	55 (27.6)
Sent an SMS text message via mobile phone before			
Yes	229 (71.8)	184 (80.3)	45 (19.7)
No	90 (28.2)	61 (67.8)	29 (32.2)
Used mobile phone for health information before			
Yes	106 (33.2)	85 (80.2)	21 (19.8)
No	213 (66.8)	160 (75.1)	53 (24.9)
Used mobile phone to set alarm for taking medication			
Yes	53 (16.6)	45 (85)	8 (15)
No	266 (83.4)	200 (75.2)	66 (24.8)
Received SMS text messages from health organization before			
Yes	39 (12.2)	31 (79.5)	8 (19.5)
No	280 (87.8)	214 (76.4)	66 (23.6)
Consulted health care professionals			
Yes	34 (10.7)	26 (76.5)	8 (23.5)
No	285 (89.3)	219 (77)	66 (23)
Used the internet to browse health-related data			
Yes	26 (8.2)	20 (77)	6 (23)
No	293 (91.9)	225 (76.8)	68 (23.8)
Frequency of mobile phone use			
Always	286 (89.6)	229 (80.1)	57 (19.9)
Sometimes	33 (10.3)	16 (48.5)	17 (51.5)
Changed your subscriber identity module (SIM) card in the last 12 months			
Yes	48 (15)	35 (72.9)	13 (27.1)
No	271 (85)	210 (77.5)	61 (22.5)
Have an additional SIM card			
Yes	22 (6.9)	20 (90.9)	2 (9.1)
No	297 (93.1)	225 (75.8)	72 (24.2)
Switch off your mobile phone during daytime			
Yes	47 (14.7)	34 (72.3)	13 (27.7)
No	272 (85.3)	211 (77.6)	61 (22.4)
There are times or places when calls are not answered			
Yes	108 (33.9)	82 (75.9)	26 (24.1)
No	211 (66.1)	163 (77.5)	48 (22.7)
There are times, places, or situations when unknown calls are unanswered			
Yes	100 (31.3)	75 (75)	25 (25)
No	219 (68.7)	170 (77.6)	49 (22.4)
Locked the mobile phone with a password			

Mobile phone use patterns	Total, n (%)	Willingness to receive SMS text messages, n (%)	
		Yes	No
Yes	164 (51.4)	132 (80.5)	32 (19.5)
No	155 (48.9)	113 (72.9)	42 (27.1)
No	223 (69.9)	182 (81.6)	41 (18.4)
Shared the mobile phone with others in the house			
Yes	95 (29.8)	64 (67.4)	31 (32.4)
No	224 (70.2)	181 (80.8)	43 (19.2)
Can send an SMS text message			
Yes	277 (86.8)	219 (79.1)	59 (209)
No	42 (13.2)	26 (61.9)	16 (38.1)
Can read an SMS text message			
Yes	287 (90)	226 (78.7)	61 (21.3)
No	32 (10)	19 (59.4)	13 (40.6)
Deleted an SMS text message without reading			
Yes	18 (6.3)	17 (94.4)	1 (5.6)
No	269 (93.7)	211 (78.4)	58 (21.6)
Likelihood of an SMS text message to be seen by others			
Very likely	26 (8.1)	17 (65.4)	9 (34.6)
Likely	57 (17.9)	38 (66.7)	19 (33.3)
Unlikely	71 (22.3)	55 (77.5)	16 (22.3)
Very unlikely	165 (51.7)	135 (81.8)	30 (18.2)
Used the internet via your mobile phone			
Yes	151 (47.3)	124 (82.1)	27 (17.9)
No	168 (52.7)	121 (72)	47 (28)
Chatted with friends and relatives			
Yes	143 (94.7)	123 (86)	20 (14)
No	8 (5.3)	1 (12.5)	7 (87.5)
Used the mobile phone to send emails			
Yes	88 (58.3)	77 (87.5)	11 (12.5)
No	63 (41.7)	47 (74.6)	16 (25.4)
Used the mobile phone to browse information			
Yes	46 (30.5)	39 (84.8)	7 (15.2)
No	105 (69.5)	85 (81)	20 (19))
Used the mobile phone for entertainment			
Yes	48 (31.8)	42 (87.5)	6 (12.5)
No	103 (68.2)	82 (79.6)	21 (20.4)

Table 3. Attitude and willingness to receive short message service (SMS) text message–based mHealth interventions among pregnant women attending antenatal care follow-up at health centers in the Gondar Town Administration, Northwest Ethiopia, 2017.

Attitude and willingness to receive SMS text message	Pregnant women, n (%)
Willing to receive SMS text messages (n=416)	
Yes	296 (71.2)
No	120 (28.8)
Reason not to be willing (n=120)	
Ruins privacy	50 (41.7)
SMS text message is annoying	2 (1.6)
Difficult to operate	54 (45)
Not important	14 (11.7)
Preferred time to begin receiving SMS text messages (n=296)	
Before 1 month	117 (39.5)
From 3 months	163 (55.1)
From 6 months	10 (3.4)
From 9 months (before birth	6 (2.0)
Preferred time of the day for receiving SMS text messages (n=296)	
Morning (8 am-before 12 pm)	59 (19.9)
Afternoon (12 pm-before 4 pm)	20 (6.8)
Evening (4 pm-before 8 pm)	38 (12.8)
Any time	179 (60.5)
Preferred frequency (n=296)	
1 per week	223 (75.3)
3 per week	70 (23.6)
5 per week	2 (0.7)
7 per week	1 (0.3)
Will pay for the service (n=296)	
Yes	232 (78.4)
No	64 (21.6)
Preferred pregnancy information to receive (n=296)	
Activities or things to avoid	
Yes	285 (96.3)
No	11 (3.7)
When to call a doctor	
Yes	107 (36.1)
No	189 (63.9)
Diet	
Yes	236 (79.7)
No	60 (20.3)
Appointment reminders	
Yes	209 (70.6)
No	87 (29.4)
What to expect at various stages of pregnancy	

Attitude and willingness to receive SMS text message	Pregnant women, n (%)
Yes	249 (84.1)
No	47 (15.9)
Physical activity	
Yes	88 (29.7)
No	208 (70.3)
Pregnancy and delivery courses	
Yes	268 (90.5)
No	28 (9.5)

Table 4. Bivariable and multivariable analyses of factors with the willingness to receive short message service (SMS) text message–based mHealth interventions to improve antenatal care (ANC) among pregnant women attending ANC at health centers in the Gondar Town Administration, Northwest Ethiopia (N=416).

Factors	Willingness, n		Crude odds ratio (95% CI)	Adjusted odds ratio (95% CI)
	Yes	No		
Age (years)				
15-24	133	27	2.810 (1.729-4.569)	2.869 (1.451-5.651)[a]
≥25	163	93	Ref[b]	Ref
Place of residence				
Urban	255	83	2.773 (1.667-4.612)	—
Rural	41	37	Ref	—
Educational level				
Cannot read and write	34	36	Ref	Ref
Informal education	13	8	1.721 (0.634-4.666)	5.032 (0.792-31.978)
Primary	78	32	2.581 (1.383-4.815)	3.040 (1.001-9.230)[a]
Secondary and above	171	44	4.115 (2.318-7.305)	4.995 (1.489-14.773)[a]
Type of mobile phone[c]				
Smart	101	19	2.030 (1.136-3.627)	—
Standard	144	55	Ref	—
Frequency of mobile phone use[c]				
Always	229	57	Ref	Ref
Some times	16	17	0.234 (0.112-0.492)	0.319 (0.141-0.718)[a]
Lock mobile phone with a password[c]				
Yes	132	32	0.110 (0.652-1.102)	—
Share mobile phone with others in the house				
Yes	64	31	Ref	—
No	181	43	2.039 (1.181-3.508)	—
Use internet[c]				
Yes	124	27	1.784 (1.044-3.047)	—
No	121	47	Ref	Ref

[a] Statistically significant at *P*<.05.

[b] Ref: reference.

[c] Participants with mobile phone ownership, n=319.

Discussion

Principal Findings

This study shows that access to mobile phone among pregnant women attending ANC at health centers in the Gondar Town Administration was high, with over three-quarters of women owning phones in this study. In addition, age, educational level, and frequency of the mobile phone use were among the notable factors associated with the willingness of pregnant women to receive SMS text message–based mHealth interventions.

The mobile phone ownership of women in this study (319/416, 76.7%) is lower than that reported in studies from Argentina (93.2%) [19] and South Africa (84%) [21]; this discrepancy could be attributed to the difference in the information and communication technology infrastructure and the socioeconomic status among countries. In addition, this is lower than studies conducted in Nigeria among women attending a tertiary facility for childhood immunization (99%); this disparity could be attributed to the study setting—a tertiary hospital—which mostly serves urban residents. Another possible explanation could be the difference in the information communication development index [22]. The mobile phone ownership in this study is nearly similar with that reported by a study conducted in Kenya (74.3%) [23]; it is also nearly similar with that reported by a study conducted in Ethiopia among antiretroviral therapy (ART) patients (76.1%) [24]. The possible explanation for this could be the similarity between study areas. This study found that the mobile phone ownership is much higher than the Ethiopian general mobile (SIM) population, which was reported to be only 48% [20]; this difference could be attributed to the study setting, which was one of the major towns in Ethiopia. In this study, most respondents were urban residents who had better access to telecommunication services. Hence, the findings of this study might not be generalizable to other areas of the country, especially in the rural communities.

In addition, 90.0% (287/319) and 86.8% (277/416) of current mobile phone owners could read and send an SMS text message, respectively, making an SMS text message–based intervention technically feasible. Furthermore, there is evidence that respondents were willing to receive SMS text message–based interventions, with a majority wanting the messages to begin early during pregnancy at 3 months, and a preference for once-weekly messages. Similar high willingness rates for SMS text message–based interventions have been observed in Argentina (96%) [19], South Africa (under option B+, 88.1%) [25], and Kenya (92%) [23]. Moreover, there is evidence of health-seeking behavior by pregnant women who wanted to receive information on what to avoid during pregnancy, diet, and information on pregnancy and delivery course

From those who were willing to receive SMS text messages, about 21.6% (64/296) of respondents were not willing to pay for SMS text messaging on current tele tariff rates, even though the benefit was clearly stated. An explanation for this could be that ANC services in Ethiopia are provided free of charge by the Ethiopian government and, thus, mothers might not want to take up any new costs. This finding has important implications for program managers and designers, as they may need to devise alternative payment mechanisms for SMS text messages in future intervention strategies.

This study identified some factors significantly associated with the willingness to receive SMS text message–based mHealth interventions among pregnant women. Younger pregnant women were more likely to be willing to receive SMS text messages; this result is consistent with a study from Kenya [26] and a study conducted in Ethiopia among ART patients [24].

This analysis indicated that women who achieved secondary or higher education were more likely to be willing to receive SMS text message–based mHealth interventions. This study is in line with a study from Ethiopia among ART patients [24] and Nigeria among women willingness for child immunization [27]. The result suggests that implementing the SMS text message–based mHealth intervention is particularly more feasible in the younger age group and more educated ones. However, it might be a potential drawback to implementing the SMS text message–based mHealth intervention program because about 21.6% (64/296) of respondents have no primary schooling; this highlights the influence of maternal educational status on the ANC utilization, as confirmed by other evidence [5]. Furthermore, it implies that before implementing the SMS text message–based mHealth intervention to improve the prenatal care utilization, apart from considering access to mobile phones, barriers that are related to the socioeconomic conditions of end users (especially the educational status) need to be fully explored and addressed.

This study shows that the place of residence, source of information for ANC, using the internet through mobile phones, mobile phone type, and mobile phone usage privacy variables, like locking the mobile phone with a password, and sharing a mobile phone with others were not found to be markedly associated with the willingness.

Limitations

There are some limitations to this study. As the study was an institution–based cross-sectional survey, only respondents who came for ANC visit were interviewed, thereby excluding those who did not visit the health centers. Moreover, this study was conducted at health centers in a major town or urban administration, which could have overstated the accessibility of women to mobile phones and their willingness to receive the SMS text message–based mHealth intervention. In addition, the survey was interviewer-administered, and even if we used neutral interviewers, there might be an interviewer and social desirability bias that could have made more participants to respond in the affirmative. These limitations have to be considered when generalizing these results.

Conclusions

A high proportion of respondents attending ANC clinics in a resource-poor urban setting of Ethiopia have mobile phone access and are willing to receive SMS text message–based mHealth interventions. Thus, mobile phone–based interventions to improve maternal health should be tried and explored further. Moreover, age, educational status, and frequency of the mobile phone use are significant factors associated with the willingness.

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Authors' Contributions

BFE contributed to conception and design or acquisition of data, data collection supervision, data analysis, data interpretation, and manuscript preparation. BT and ANW agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. BT and ANW were involved in drafting the manuscript or revising it and have agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The manuscript was critically reviewed and edited by BT, RL, and MW.

Conflicts of Interest

None declared.

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Abbreviations

ANC: antenatal care
AOR: adjusted odds ratio
ART: antiretroviral therapy
SIM: subscriber identity module or subscriber identification module
SMS: short message service

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Original Paper

Clinical Adoption of mHealth Technology to Support Pediatric Cystic Fibrosis Care in Sweden: Qualitative Case Study

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Abstract

Background: Mobile health (mHealth) technologies have potential to improve self-management and care co-ordination of pediatric chronic diseases requiring complex care, such as cystic fibrosis (CF). Barriers to implementation include the lack of support and infrastructure to use mHealth in the clinical microsystem. Coproducing mHealth technology with patients, clinicians, and designers may increase the likelihood of successful integration into the clinical setting.

Objective: This study explored the development, adoption, and integration of a new, co-produced mHealth platform (Genia) for the management of pediatric CF in Sweden.

Methods: A retrospective, qualitative case study approach was used. The case was defined as the process of introducing and using Genia at the Pediatric Cystic Fibrosis Center at Skåne University Hospital in Lund, Sweden. Data sources included interviews, presentations, meeting notes, and other archival documents created between 2014 and 2017. To be included, data sources must have described or reflected upon the Genia adoption process. Iterative content analysis of data source materials was conducted by 2 qualitatively trained researchers to derive themes characterizing the mHealth clinical adoption process.

Results: In total, 4 core themes characterized successful clinical integration of Genia in Lund: cultural readiness to use mHealth; use of weekly huddles to foster momentum and rapid iteration; engagement in incremental "Genia Talk" to motivate patient adoption; and co-design approach toward pediatric chronic care.

Conclusions: Principles of quality improvement, relational co-ordination, user-centered design, and coproduction can facilitate the integration of mHealth technology into clinical care systems for pediatric CF care.

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KEYWORDS

cystic fibrosis; mHealth; mobile phone; pediatrics; qualitative case study; technology

Introduction

Longitudinal care of children diagnosed with cystic fibrosis (CF)—an autosomal recessive genetic disorder affecting lung capacity—is characterized by substantial personal, familial, and medical burden [1,2]. To decelerate decline in lung function, children must engage in respiratory and physical therapies up to 2 hours per day, adherence to which often decreases as children age through adolescence [3]. Guidance from health care providers is frequently disconnected from this daily routine and the personal goals of pediatric CF patients [4]. For pediatric CF, this disconnectedness derives in part from the traditional model of episodic care delivery, which hinders an uninterrupted approach and may result in fragmented clinical care [5]. The challenge to co-ordinated care particularly impacts young people during a developmentally vulnerable time, when they move from clinician-regulated pediatric care to increasingly autonomous self-management of their illness [6]. Successful transition to adult CF care is dependent on consistent, appropriate, and increasingly independent maintenance of a care regimen [7]. Encouraging these patterns of behavior in late childhood and early adolescence fosters stability and reliability of personal management of chronic illness into adulthood [8].

Mobile health (mHealth) technology-based platforms offer a transformational mechanism for improving clinical care in both preventive medicine and chronic disease management [9,10]. One strength of mHealth as a disease management tool is its ability to leverage existing mobile technology infrastructure and the ubiquity of smartphones across populations [11]. For adolescents, who are frequent users of mobile technology, mHealth applications show potential as a strategy for improving self-management of and adherence to treatment regimens for numerous chronic conditions [12]. Successful use of technology-based support systems to foster self-management, however, is not without challenges. Usability studies identify barriers to the uptake of and adherence to various mHealth and electronic health systems used by clinicians and patients [13,14]. These barriers include low self-efficacy with mHealth platforms; perceptions that the technology will not enhance clinical outcomes; privacy and security concerns; and lack of infrastructure to support the use of mHealth applications [15,16].

Integral involvement of end users in the development of mHealth applications—such that the technology is “co-produced” by designers, clinicians, and patients—may be a strategy to overcome implementation challenges. Coproduction refers to the joint creation of health care services for managing the treatment of a health condition [17]. By engaging end users in mHealth development, this joint design approach may avoid common implementation barriers and enhance the likelihood that these new technologies will be adopted in clinical settings and used by target audiences [18,19].

The purpose of this study was to provide a retrospective case analysis of the development, adoption, and integration of a new, co-produced mHealth platform for the management of pediatric CF in Sweden. Genia is an app-based patient support system (PSS) designed to foster collaborative care and enhance self-management among pediatric patients living with chronic conditions. In 2014, Genia was introduced to the Pediatric Cystic Fibrosis Center at Skåne University Hospital (Lund, Sweden) in its design phase and codeveloped with adolescent patients and CF providers at the center. The adoption of Genia in Lund was highly successful, with a majority of pediatric CF patients using the app. The aim of this case study was to examine the introduction of Genia in Lund to identify successful contributors to the clinical integration of a technology-based PSS, which may be disseminated to other pediatric CF centers in Sweden and abroad and potentially to other pediatric chronic conditions.

Methods

Mobile Health Patient Support System: Genia

Genia is a mobile iOS PSS created by a Swedish-based company Upstream Dream to optimize consensus-building in pediatric care by improving communication between patients and clinical teams, fostering disease self-management and aligning patients’ goals with clinical treatment plans (see Figure 1).

By doing so, Genia aims to facilitate timely, meaningful, and appropriate clinical care and ultimately to improve patients’ quality of life. Through Genia, patients (or parents, depending on the patient’s age) can record daily health observations and symptoms between visits (eg, physical activity or gastrointestinal problems), track medications, and complete previsit reports, including treatment preferences and goals, prior to a clinical appointment. This patient-reported information allows patients to document their disease activity and preferences in the real-time between clinical visits (see Figure 2).

Patient data are then integrated into the National CF Quality Registry (ie, a registry established in 1992, encompassing all 21 regional health care systems or payors in Sweden, which longitudinally follows every CF patient in Sweden) and the care flow within the clinical setting. Clinical providers—including physicians, physiotherapists, and others—are able to review patients’ previsit reports as an Adobe PDF file in the CF registry prior to the clinical visit to better inform the visit and foster opportunities for shared decision making and goal setting. Patients and providers also use Genia to collaboratively document agreed upon therapeutic decisions, actionable steps, and other information derived during the clinical visit. Genia thus aims to foster patient self-management, build trusted patient-provider relationships, and increase compliance with mutually agreed upon care plans.

Grounded within principles of user-based design [20], feedforward systems [21], and coproduction [17], functional features of Genia were created and tested through small-scale, iterative design cycles with patient and family representatives and clinical CF providers within the Lund Pediatric CF clinical microsystem. These learning collaboratives formed the backbone of Genia development by ensuring that technological modifications of the app were grounded in end user’s lived experiences. This user-centered perspective is also illustrated in the key features of the app, which identify patients as the experts in their disease state and better enable them to provide their voice to the care they receive. Genia is currently available for download from the iTunes App Store in an iOS platform in Swedish and English.

Figure 1. Genia flow.

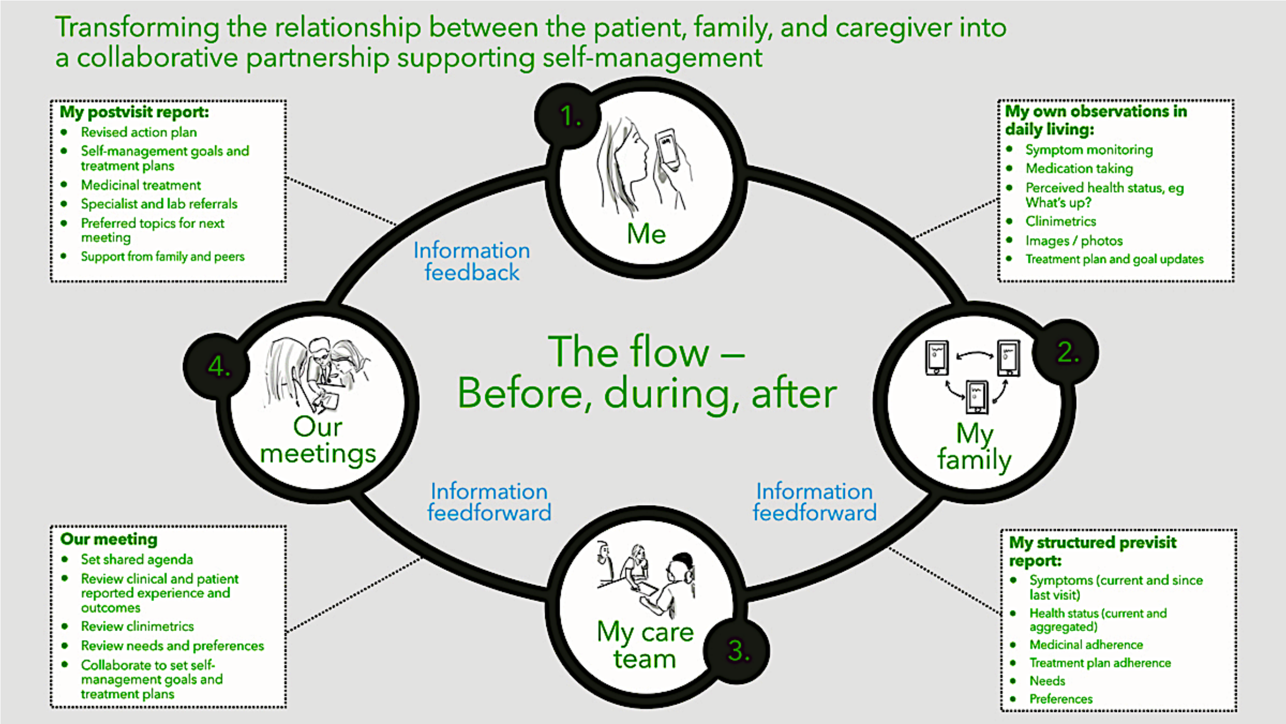
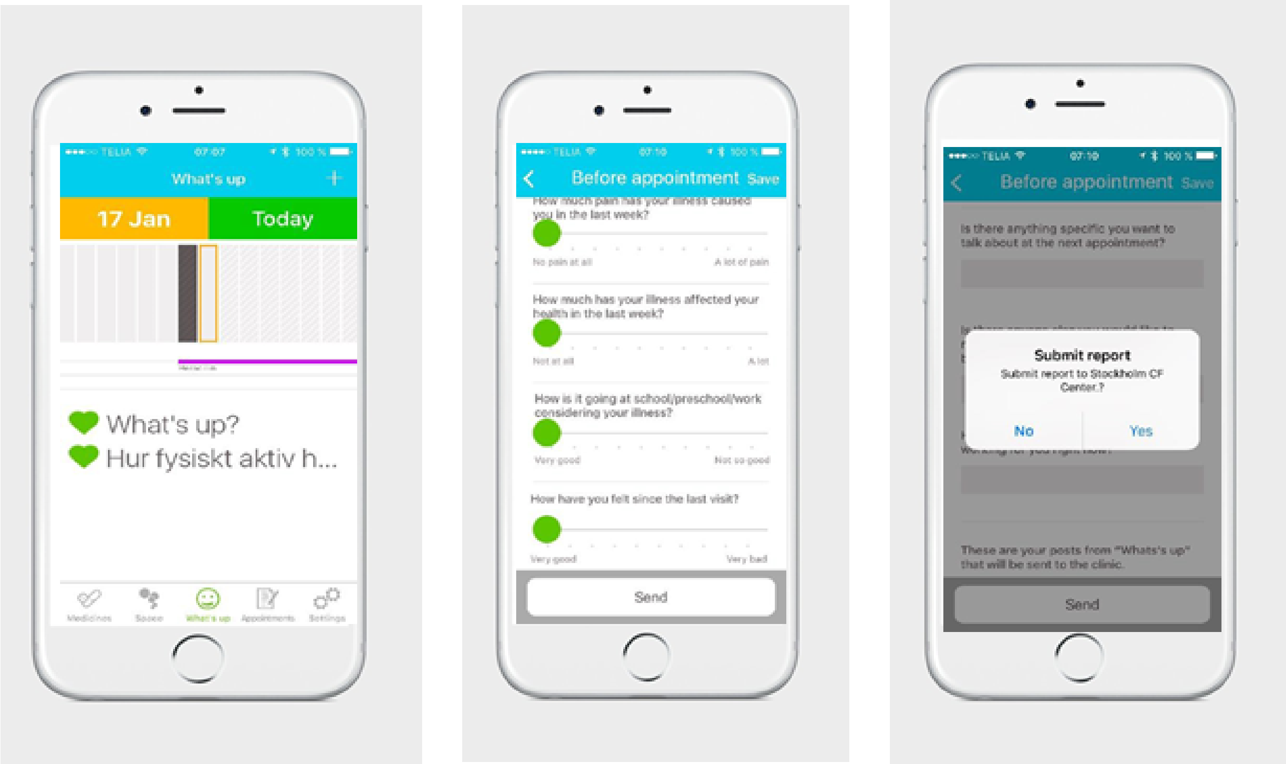


Figure 2. Screenshots of sample Genia app pages developed Upstream Dream.



How much pain has your illness caused you in the last week?

How much has your illness affected your health in the last week?

How is it going at school/preschool/work considering your illness?

How have you felt since the last visit?

Is there anything specific you want to talk about at the next appointment?

Submit report to Stockholm CF Center.?

These are your posts from "Whats's up" that will be sent to the clinic.

Study Design

We conducted a retrospective, descriptive, qualitative case study [22] of Genia adoption in Lund as part of a larger formative evaluation of Genia within the clinical pediatric CF setting in Sweden. A qualitative approach was selected to allow for an in-depth, inductive examination of data within a naturalistic setting (ie, Lund), enhancing the validity of findings. The case study method was considered most appropriate for several reasons, including its holistic approach to describing how and why Lund was successful; the emphasis on exploration of a phenomenon in the "real-life" clinical settings where the researchers observe but do not manipulate behaviors or processes under examination; and the ability to conduct a retrospective analysis by examining historical artifacts documenting the Genia development and adoption processes [22]. This study was reviewed and determined to be exempt by the Committee for the Protection of Human Subjects at Dartmouth.

Study Setting

The “case” was defined as the process of introducing and using Genia at the Pediatric Cystic Fibrosis Center at Skåne University Hospital. Located in Lund, Sweden, Skåne University Hospital represents 1 of only 4 pediatric hospitals in Sweden. The Lund CF Center is a regional center for specialized CF care in accordance with the European Cystic Fibrosis Society Standards of Care and serves approximately 60 pediatric patients annually. The pediatric clinical team in Lund consists of 4 physicians, 2 nurses, 2 physiotherapists (ie, physical therapists), 1 dietician, 1 social worker, and 1 psychologist. This team meets weekly to discuss care plans and clinical issues with incoming patients. Pediatric CF patients located geographically close to the center typically visit the clinic every 2 months. Those living outside the region visit with the Lund clinical staff 2-4 times per year. Lund has a long tradition of emphasizing the role of physiotherapy for the care of pediatric CF patients. Reflecting this tradition, at each clinical appointment, physiotherapists have an hour-long appointment with the patient prior to the physician’s visit with the patient.

Genia was initially introduced to the Lund CF Center in late 2014. By July 2017, the Lund CF clinical staff indicated successful integration of Genia into their practice, defined as the percent of patient Genia users and Genia use within care team meetings. Specifically, 87% of Lund CF pediatric patients were members of the Genia PSS, and 85% of all care team meetings (ie, clinical visits between pediatric CF patients and care providers) were supported by Genia through the use of a previsit report.

Data Sources

Consistent with the case study methodological approach, we employed a data triangulation strategy in which data were extracted from multiple sources that were created between late 2014 and July 2017. Data sources included interviews with Lund providers and the Genia design team, design and implementation meeting notes, design team and clinical team emails, archived presentations, Genia progress reports, and other documents. To be included in the analysis, data sources must have described or reflected upon the early adoption and integration process of Genia in Lund. Some archival data sources were translated from Swedish to English using Google translate or by a bilingual member of the Genia design team. All data sources were organized and condensed into a tabular case record in Microsoft Excel in preparation for analysis [22].

Data Analysis

Data analysis was conducted by 2 qualitatively trained researchers unaffiliated to either the Genia design team or the pediatric Lund CF team. We applied iterative, conventional content analysis [23] in the coding process. Conventional content analysis is an appropriate approach when there is not a strong theoretical framework directing the analysis, the aim of the investigation is descriptive, and study design is primarily observational [23]. Because of this, our analytic approach was primarily inductive, in which we allowed themes to emerge from the raw data. We identified themes within 3 temporal stages of Genia adoption: (1) PSS introduction to the CF team, (2) facilitators of widespread adoption, and (3) integration into clinical flow.

The first researcher conducted the initial data analysis using the aggregate case record as the full data source. Following immersive review of the data, an initial round of preliminary coding was performed for the entire case record [24]. Due to the varied types of data sources, we employed multiple coding techniques, including descriptive coding to document the data source and timeline and process coding to identify the strategic actions during Genia adoption and implementation [24]. When possible, we also used direct words or phrases from the data source as emergent, *in vivo* codes. During the second round of coding, we looked for patterns of codes within and across the temporal stages of Genia adoption, expanding, synthesizing, reframing, or rephrasing codes as necessary. Larger themes were described and illustrated with exemplars. The second researcher reviewed the case record as well as the thematic and illustrative evidence. Clarifications and discrepancies were resolved through consensus discussion. To enhance the credibility of findings, the final set of themes was provided for review to 1 member of the pediatric Lund CF team and 2 members of the Genia design team. No changes were made after their review.

Results

Principal Results

In total, 4 core themes characterized the successful adoption and integration of Genia in Lund. Illustrative quotes are excerpted from interviews with pediatric Lund CF providers.

Cultural Readiness to Use Mobile Health

Attitudinal and structural characteristics of Lund contributed to a pre-existing culture that was receptive to the introduction of a new mHealth technology. The Lund provider team had undertaken informal quality improvement (QI) projects prior to Genia and were engaged and motivated to continue a QI-type approach to their clinical work.

> *I think we always have that in mind to work ‘Lean’ [Lean Six Sigma] and to make quality improvement better at the clinic.*

Additionally, Lund providers indicated that Genia represented a more “modern” way of engaging in their clinical work with pediatric CF patients, particularly due to its technology-based platform, and thus it was consistent with their attitudinal ethos of continual improvement.

Several structural characteristics of Lund also contributed to the success with which the clinic adopted Genia. The historical prominence of the physiotherapist in pediatric CF care management yielded a trusted, internal point person to manage the effort of introducing Genia. The lead physiotherapist in Lund served as the primary “champion” of Genia and was the person who initially familiarized the wider clinical team to the app. Because of her role, she was influential in the decision by other members of the clinical team to try Genia.

> *It's a tradition in Sweden and especially in Lund that the physio[therapist] is very important and mostly everyone listens to the physio. So if the physio says something, I really believe that everyone is listening.*

The second physiotherapist in Lund supported the lead physiotherapist's efforts and likewise served as a Genia champion. The presence of 2 clinical champions at the site allowed for a collaborative approach and shared responsibility for the workload associated with Genia onboarding.

> *You have to be at least two to get this project working because it's hard to do everything by yourself. You need two fighting spirits.*

The physiotherapists' historical leadership role in pediatric CF care helped not only with onboarding other clinical providers to Genia but also with onboarding patients. The physiotherapists represent the most familiar clinic-based providers to the patients due to the extended time they spend with patients (ie, 1 hour) prior to each appointment. The close, trusted nature of the physiotherapist-patient relationship supported the physiotherapists' ability to introduce Genia to the Lund pediatric patients.

Finally, because the Lund CF clinic is relatively small (~60 patients) and the pediatric CF provider team is also small (ie, 11 members), logistical co-ordination and communication regarding Genia was easier. The team already met weekly to discuss patient issues; thus, integrating Genia into these team meetings was a "natural" way to incorporate Genia into a regular clinical discussion.

Weekly Huddles Fostered Forward Momentum and Rapid Iteration

Short (ie, 15 minute) weekly clinic "huddles" served as the critical process mechanism for fostering continued, forward momentum in adopting Genia in Lund. Huddles were facilitated by a Genia design team member and attended by the physiotherapist champions, other clinical team members, and adolescent CF patient "lead users." Huddles offered opportunities to provide support for using Genia, understand barriers to use, and document good practices. Huddles were characterized by a user-centered design approach, in which clinical and patient users would test features of the app during the prototype development phase and provide weekly feedback to the Genia design team who would modify the app based on this feedback. The huddles thus facilitated iterative feedforward or feedback problem-solving cycles that allowed for rapid identification of challenges to effective Genia use and rapid implementation of responsive action plans. For example, during one huddle, discomfort with using the technology was revealed as a potential barrier to use. The design team was able to quickly develop an instructional video, which clinical team members could view repeatedly to increase their proficiency with the app. In another example, the huddle discussions revealed that receiving previsit reports throughout the week was hard to manage within the clinical workflow. The team instead tried receiving previsit reports every Sunday night triggered by an auto-prompt sent via the app to patients over the weekend; this proved to be more clinically manageable and further helped to structure the Monday huddle meetings. The team's commitment to weekly meetings ensured that progress continually moved forward.

> *It's been very important to have weekly contact with Genia. To remind you to 'Think Genia!'.*

Codecision making during the huddles about Genia development, and a patient-centered approach in which the pediatric CF patients and the clinical providers were considered the "experts," both fostered engagement by the primary end users and enhanced motivation for continued Genia use. Patient and family lead users offered new ideas for upcoming iterations, provided a platform for peer support, and operated as ambassadors for spread. Huddles also fostered motivation through sharing of successful patient or provider stories of Genia use and lessons learned. Thus, the huddles represented the primary mechanism by which Genia progressed from initial design and limited use to wider scale adoption.

Engagement in Incremental "Genia Talk" Motivated Patient Adoption

The physiotherapists in Lund were primarily responsible for introducing Genia to patients. Several strategies for doing so were collectively referred to as "Genia Talk" by the physiotherapists. When possible, the physiotherapists introduced Genia to patients as early as possible in their care management. This communicated to the patient the integration of Genia with the usual care offered by the clinic.

> *The physiotherapists made Genia their tool. They signal very clearly to all patients that Genia is a way of working for them. This is how we do it in Lund.*

Physiotherapists utilized a tailored, stepwise approach to the introduction of the app. Rather than showing patients (and their families) the entire app all at once, the physiotherapists selected one feature of the app to focus on with the patient at a particular visit (eg, how to record a daily observation), tailored to a current clinical need. At the next clinical visit, the physiotherapists would check on the progress with that feature of the app and introduce another new feature (eg, how to track medications).

> *We present Genia and what we can, together, benefit from in the app. We don't try to present everything at once, but take small steps forward.*

Additionally, at every visit, the physiotherapist would ask to collaboratively complete the previsit report in Genia with the patient if the patients had not completed the previsit reports on their own. This new process was initially tested by one physiotherapist as a response to patients forgetting to complete the previsit report prior to arriving at the clinic; due to its success in activating patients to use Genia and helping to shape their expectations about the importance of the report, this process was subsequently normalized within the clinical setting. This supported and gradual approach to onboarding patients was a central feature of the successful adoption of Genia by patients. By allowing patients to learn the app in a way that was responsive to their current needs, patients incrementally experienced the heightened value of Genia over time without increased burden. As more and more patients began using the app in a successful way, word-of-mouth spread patient interest in using Genia, which also contributed to a transition to wider usage.

Co-Design Approach Toward Pediatric Cystic Fibrosis Care

Emerging from the weekly huddles and improved engagement with patients was a process characterized by co-design strategies, where conversations and interactions were iterative and collaborative. These co-design strategies were profiled by the Lund providers in contrast to previous practice strategies marked by one-sided conversations and asymmetric information sharing. The co-design strategy ensured that the app was viewed as relevant, usable, and valuable to both patients and clinicians, thus overcoming potential barriers to implementation during the design phase rather than waiting until after the app was completed. Thus, the coproduction of the app itself was inherent to the success of the integration process.

In Genia-supported CF care, patients were able to share challenges and insights prior to meeting with their care team, which permitted care team members to prepare and more efficiently and effectively interact with them. One clinician said, “Being prepared for the visit, both family and patient” was made possible by the previsit report function through Genia. The functionality of Genia also permitted the cocreation of care notes, which was an outcome driven by the previsit report function. The efficiency of the structured visit, and “knowing what to ask,” helped the clinicians focus on the treatment plans for their patients rather than on managing the visit itself.

Discussion

Principal Findings

This descriptive case study contributes to a small body of literature on technology-based interventions to improve CF self-management [25,26] and is one of the first to document the development and adoption process of an mHealth app for pediatric CF patients in a clinical setting. By illustrating successful features of integration, our findings highlight cultural characteristics of the clinical setting, which are more likely to support the feasible integration of new technologies, as well as mHealth design components that contribute to success.

This case reveals how the team-based institutional culture of CF care practice in Sweden complemented readiness for adoption of a novel mHealth patient engagement tool. Multiple characteristics of the clinic itself set the stage for successful integration, including cultural ethos of QI, desire for more modern ways of providing care, relational co-ordination within a small care team [27], and mHealth champions who represented the most influential clinical team members both within the team and with patients, and thus could foster shared aims. These characteristics, which some have referred to as an “implementation climate,” [28] essentially primed Lund for the successful adoption of Genia. Organizational readiness of the clinical setting thus plays a gate-keeping role in mHealth integration [29]. As such, it offers important insights into the selection of settings that are likely to successfully adopt mHealth technologies for pediatric chronic illness management. This approach, however, is a resource-intensive process. Cultural and contextual characteristics of many pediatric clinical settings may reduce their ability to meet weekly for QI huddles or to engage patients in the intensive mHealth design process.

Weekly team huddles during the adoption phase of Genia enhanced routinization of communication practices and the collective belief in the value of a technology-based application to engage CF patients. In essence, these weekly huddles served as the primary mechanism that operationalized the iterative, user-focused design process. Ample research on the development of mHealth technology promotes the incorporation of end user in the design process [30]. However, often this user input is incorporated late in the design phase or episodically. Our case demonstrates that weekly meetings between key stakeholders (ie, patients and clinicians) and the technology design team beginning early in the app development process were critical to integration. Not only did this human-centered design approach [30] allow for frequent, iterative design cycles based on user feedback (ie, feedforward or feedback information cycles), it also enhanced the commitment to use Genia due to a collective feeling that Genia is “for us, by us.”

The gradual, patient-specific onboarding process used by the physiotherapists enabled patients to learn to use Genia in an incremental manner. By highlighting features of the app that were useful to patients as needed, patients saw the increasing value of Genia without being overwhelmed by the capabilities of the technology. Since ease of use is one of the most frequently cited barriers to mHealth adoption [13,15], this slow and steady process of exposure, always with the direct help of the physiotherapist, was central to patients’ positive experiences with the app.

Limitations

There are several limitations in this case study report. The sample of qualitative data was relatively small and was examined retrospectively, which limited our ability to pursue clarification of historical artifacts. Results presented here should be regarded as preliminary. Our case study examined only one clinical setting in Sweden, limiting the generalizability of the findings. Future work should examine the Genia adoption process at other pediatric CF centers to determine whether facilitators identified in this study are transferable to other clinical settings. Additionally, examining how care teams collaborated in their use of Genia with respect to specific care regimens—such as nutrition or physical activity—would be useful to reveal the microsystem-level utility of the app. We recognize that direct patient’s perspectives (eg, patient interviews) were not included in the data sources, as this case was focused on the implementation and dissemination of the technology within the Lund clinical setting and among its clinicians. Patient perspectives are necessary to directly examine how patients perceived the clinical integration of Genia in Lund. Our report may have been limited by the Swedish and English language challenges of communicating across cultures. Although the case report was developed in partnership with bilingual partners and many clinicians spoke both English and Swedish, the nuance of the details must be read with caution as translations and interpretations may vary. Finally, this study only examined the process of adoption and implementation of

Genia and did not examine the impact of Genia on patient outcomes, such as improved self-management, treatment adherence, or quality of life. Future studies among patients are needed to determine whether Genia improves care compliance to and self-management of CF, and ultimately patient health outcomes. These offer important research directions for the use of Genia by pediatric CF patients.

Conclusions

This qualitative case study offers preliminary evidence for strategies necessary for the successful adoption of an mHealth app within a pediatric chronic illness clinical setting. Although originally designed for pediatric patients with CF, the process described here could be applied to any pediatric chronic illness requiring extended self-management and complex care with multisector teams.

Acknowledgments

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Conflicts of Interest

AH, MM, and RPB are employees of Upstream Dream, a private company that developed the Genia app. ML, SG, and GK are affiliated with The Geisel School of Medicine at Dartmouth and have no financial conflicts of interest to report.

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Abbreviations

CF: cystic fibrosis
mHealth: mobile health
PSS: patient support system
QI: quality improvement

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Original Paper

Assessing the Perceptions of Inspiratory Muscle Training in Children With Cystic Fibrosis and Their Multidisciplinary Team: Mixed-Methods Study

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Abstract

Background: Little is known about the opinions or perceived benefits of an inspiratory muscle training intervention in patients with cystic fibrosis and their multidisciplinary team.

Objective: The aim of this qualitative study was to examine patients' and multidisciplinary teams' views on inspiratory muscle training to inform and tailor future interventions.

Methods: Individual, semistructured interviews were conducted to evaluate participants’ perspectives of a 4-week inspiratory muscle training intervention. In this study, 8 of 13 individuals involved in the inspiratory muscle training program (5 children aged 11-14 years; 2 physiotherapists; and 1 respiratory physician) participated. Interviews were transcribed verbatim, analyzed using thematic analyses, and then coded into relevant themes.

Results: Four key themes emerged: acceptability, facilitators, barriers, and recommendations. While fun, enjoyment, and improved perceived physical ability were reported by children and their multidisciplinary team following the inspiratory muscle training program, the multidisciplinary team identified factors such as time and cost as key barriers.

Conclusions: A short inspiratory muscle training program was perceived to have positive effects on the physical ability and psychosocial health of children with cystic fibrosis. These findings highlight the importance of obtaining participants’ and multidisciplinary teams' perceptions and recommendations to ensure the efficacy and optimal design of future inspiratory muscle training protocols.

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KEYWORDS

cystic fibrosis; health perceptions; inspiratory muscle training; mobile phone; pediatrics; qualitative

Introduction

Cystic fibrosis (CF) is the most common inherited, life-shortening condition in the United Kingdom [1]. Despite recent advances in pharmacological interventions [2], the median life expectancy remains around 40 years [1]. Characterized by recurrent respiratory infections, breathlessness, cough, and gastrointestinal complications, CF is a multisystem disease requiring many hours of daily therapy [3]. With no cure available currently, the development or refinement of treatment strategies that increase or maintain the quality of life (QoL), exercise capacity, and respiratory function are paramount for the well-being of patients with CF.

Inspiratory muscle training (IMT), which utilizes restricted airflow breathing exercises to increase the mechanical load on the external intercostal muscles and diaphragm, is a subject of research interest. The increased muscular load engendered by IMT provides a stimulus to elicit a hypertrophic response [4], similar to that observed in response to strength training in limb muscles [5]. Substantial improvements in respiratory muscle endurance [6,7], respiratory muscle strength, and vital capacity [8] have been reported in patients with CF who have undertaken IMT, and there is some evidence for a positive effect on lung function and QoL [4]. Despite the potential benefits of IMT, there is a lack of consensus regarding its routine use in clinical practice due to marked variations in study protocols, small sample sizes, and lack of psychosocial outcome measures [5,9]. Specifically, only two studies have reported psychosocial health as an outcome, reporting that anxiety and depression scores decreased in an IMT group that trained at 80% of their maximal effort [4] and a trend toward an improved QoL with a combined IMT “whole muscle” training program [10]. Regardless of potential efficacy, many treatment strategies are limited by participants’ perceptions of, and, thus, adherence to, the intervention. Indeed, a common barrier to adherence cited by many adolescents with CF is the embarrassment of taking their treatments in front of other people [11,12]; this suggests the potential utility of home-based interventions, such as IMT, which may increase adherence to treatments in adolescents with CF. However, no studies are presently available regarding the perceptions, opinions, or recommendations of participants, or indeed of a multidisciplinary team (MDT), concerning IMT. Furthermore, the mean age of participants in IMT studies is approximately 18.5 years [13]. With the average life expectancy of around 45.1 years, participants in these studies are effectively middle aged, and therefore, further research in the younger CF population is warranted [14]. This lack of evidence makes it difficult to establish the overall efficacy of IMT as a therapeutic strategy for adolescents with CF [9]. Therefore, the aim of this study was to ascertain the views of children, and their respective CF MDT, in relation to IMT following a 4-week training program.

Methods

In this study, 5 children (age, 11-14 years) were included if they met the following criteria: (1) took part in the pilot study of IMT conducted by Swansea University; (2) had a confirmed diagnosis of CF or were a matched control; (3) had no additional non-CF illness or disease; and (4) voluntarily participated and provided written informed parental consent and child assent. MDT participants (2 physiotherapists and 1 respiratory physician) were eligible for inclusion if they provided clinical care for children with CF and had been involved in the same IMT pilot study.

Inspiratory Muscle Training

The IMT intervention consisted of participants undertaking 30 inspirations, twice a day, for 28 consecutive days using a POWERbreathe Plus device (POWERbreathe Plus LF Level 1, Gaiam Ltd E & OE, UK). A progressive approach was adopted, whereby participants initially trained at a load of 40% of their baseline maximal inspiratory pressure, increasing to 50% during weeks 3 and 4 [10]. All procedures and protocols utilized in this study were approved by the local National Health Service (NHS) ethical committee (13/LO/1907).

Qualitative Protocol—Interviews

Children and MDT members took part in individual semistructured interviews with follow-up questions. A semistructured interview includes a series of predetermined but open-ended questions, thereby allowing the interviewer to follow topical trajectories in the conversation, as well as providing interviewees freedom to express their views in their own terms [15,16]. Children’s interview questions were related to their thoughts and opinions of IMT. MDT’s interview questions were centered around their opinions of IMT, responses from patients, and IMT reflections and recommendations. All interviews were conducted by one investigator (JLM). Table 1 presents sample interview questions. All interviews were recorded and transcribed verbatim for analysis.

Table 1. Example interview questions.

Interview and topic	Examples
Children	
Inspiratory muscle training	• What did you like and dislike about the training device? • What made it easy or difficult to do the training program?
Future	• How would you react if you were asked to do this training again?
Multidisciplinary team	
Inspiratory muscle training	• What is your opinion of the IMT device? • How did the patients respond to the IMT device?
Future	• What do you think about the National Health Service adopting an IMT intervention as a treatment? • What recommendations do you have for interventions you would like to see for CF patients?

Data Analysis

All interviews were transcribed verbatim by one author (JLM) and analyzed thematically [17] using a manual approach. One author (JLM) read and familiarized the transcripts, and an initial list of codes was developed to organize the data to identify and develop themes from them [18]. A cross-examination of thematic data was undertaken by the research team in reverse, tracing verbatim quotations back to transcripts to ensure that the developed themes were grounded in the original data [19]. To ensure methodological rigor, themes and verbatim quotations were then reviewed by 3 authors to ensure findings were worthy of attention and to offer an alternative interpretation of the data [20,21]. This process continued until an acceptable consensus had been reached by the group.

Results

Five children (n=3 boys) and 3 MDTs (2 physiotherapists and 1 respiratory physician) completed the interviews. All interviews were semistructured and lasted between 30 and 40 minutes. Example verbatim quotes are provided to support the points raised with a frequency count (in brackets) to indicate the number of times the particular theme was raised. The following 4 themes emerged from the interviews: (1) acceptability; (2) facilitators; (3) barrier; and (4) recommendations.

Acceptability

Feedback from all participants was very positive regarding the acceptability of the intervention. The MDT noted children's enthusiasm, and all children reported enjoying the IMT intervention:

> *I felt really excited [to do IMT] I just wanted to have a go at it.* [Girl; n=5]

Some patients even suggested they would like to take part in future interventions:

> *I was pretty sad I didn't have to do it again. I'd happily do it again.* [Girl; n=4]

Children reported good participation and adherence to the IMT intervention due to the ease of implementation:

> *Like it was easy you just do it [IMT] at home. You don't have to go anywhere specific or special. You could just do it in your bedroom if you wanted.* [Girl; n=2]

In addition, the ease of integration into daily routine:

> *I got into it…I feel like I've always done it. When you get up in the morning, you normally eat your breakfast, get ready for school, do IMT and then quickly leave the house for the bus.* [Girl; n=5]

Most importantly, children expressed enthusiasm and enjoyment:

> *I really enjoyed it, I got into it…I feel like I've always done it.* [Boy; n=4]

Furthermore, all children perceived IMT to have a positive effect on their ability when partaking in a physical activity (PA):

> *For some reason, I don't know how, but they [lungs] almost felt like, almost got stronger. You could just breathe more freely…I could keep running for longer, I didn't have to stop and take deep breaths as much as normal.* [Girl; n=5]

Children also indicated reduced embarrassment associated with completing the treatment at home:

> *I like it [using the device at home] cause of not having all the constant questions. I don't like, well, I don't mind answering questions when people do ask [about CF], but like I am not getting caught up in it all the time in school with my friends.* [Boy; n=2]

Moreover, the CF care team reported positive feedback from their patients and high adherence:

> *They would have all liked to have kept the IMT device and carried on. In fact, one of the patients subsequently went out and bought one and uses it as part of their routine.* [Female Physiotherapist; n=3]

Akin to the children's perceptions, CF care team members believe that the IMT training schedule fit well around children's home and school schedules:

> *From a practical point of view, I think that fitted well. All feedback seemed to confirm that.* [Female Physiotherapist; n=2]

Facilitators

Unsurprisingly, the MDT highlighted the importance of family, specifically parental influence, with "sporty families" being labeled as easier to motivate to undertake an intervention and exercise:

> *If you've a sporty family its easier…Families will support them [children] most of the families were very keen on IMT. You have to get the families on board."* [Female Physiotherapist; n=3]

Not only are family facilitators influential, but peer facilitators are key, especially for children. The MDT highlighting the importance of children with CF being seen as equal to their peers:

> *It is very important to both keep them healthy and also to keep them in their peer group, you know at school and during sports activities. They need to be able to keep up with the rest of their class, so it is very, very important…A psychological benefit of being able to keep up with their peer group.* [Female Physiotherapist; n=3]

Barriers

Although it seemed the intervention was well adhered to and enjoyed thoroughly by all participants, barriers were nonetheless highlighted, although predominantly by the MDT rather than the children. The MDT highlighted the following main barriers to the implementation of IMT:

Cost

The clinical care team highlighted cost to be a major barrier in implementing IMT within the local NHS framework:

> *Obviously there is a cost implication as there is no money in the NHS for any of these things.* [Female Respiratory Physician; n=3]

Furthermore, there is a reliance on charitable income to fund airway clearance equipment:

> *Cost would be a big thing and whether it was a benefit to patients.* [Female Respiratory Physician; n=3]

However, it was accentuated that if IMT proved to be successful, the cost should be met:

> *If it is proven to be beneficial they [the NHS] are more likely to get it. If it's proven to be beneficial and improve lung function compared to the cost of some of the drugs they [the NHS] might pay for it.* [Female Physiotherapist; n=3]

Burden

Patients with CF have a high treatment burden involving daily physical therapy coupled with medication. Incorporating IMT into an already busy treatment schedule was a concern raised by the MDT:

> *It's yet another thing for us to ask them to do because they do have quite a large treatment burden…so that would be the biggest con, a time thing.* [Female Physiotherapist; n=3]

This concern was also echoed by one of the children:

> *It was extra work to do with everything else that I have to do.* [Boy; n=2]

Yet, one of the MDT had a solution, whereby an IMT program could be viable within the treatment schedule of a patient with CF:

> *Obviously you don't want it to be too much of a burden. Deciding whether it is better than other parts of their treatment and other part of their Physio and then substitute it [IMT] in could be an option.* [Female Respiratory Physician; n=1]

Family

Converse to families being deemed as facilitators, a physiotherapist reflected on previous cases, whereby children's divorced parents have had a negative impact on children's participation levels in activities:

> *The parents have divorced, and the girl lives with mum. The mum has a full-time job and mum didn't push any after-school clubs, dad was the one that did it previously. So that created a big barrier.* [Female Physiotherapist; n=1]

Recommendations

Participants were requested to comment on any changes they would make to the device and protocol. The children reported no changes, whereas the care team had numerous suggestions to improve future interventions. One of the main changes the care team suggested was the importance of knowing whether participants were adhering to the intervention:

> *I don't know if you can measure compliance, but it would be good if it [IMT] can tell us how much they actually did.* [Female Respiratory Physician; n=1]

To ensure future would adherence to IMT protocols and make the intervention attractive to children, the following was suggested:

> *Young people like to have their smartphones and apps, visual feedback in a piece of electrical equipment, that is probably the way forwards.* [Female Respiratory Physician; n=2]

In addition, implementing a competitive element was highlighted as important additions in future interventions:

> *Feedback so they know how well they are doing. They are quite competitive, so if they know the others are doing it, they'll be more motivated.* [Female Physiotherapist; n=2]

Contrastingly, despite reporting that a three times-a-day intervention fitted well into a child's routine, the MDT suggested a more time-efficient intervention to reduce the burden on patients:

> *Three times a day would be a problem, it [IMT] would have to be something regular to get them into a routine.* [Female Respiratory Physician; n=3]

Discussion

The aim of this study was to ascertain the views of children and the CF care team in relation to an IMT intervention, thereby providing population-specific evidence to inform future interventions. Results indicate that all children enjoyed the home-based intervention, while the CF care team raised concerns regarding cost and treatment burden. Overall, these results provide important insights regarding future IMT interventions, building upon the limited literature available regarding the opinions of patients, respiratory physicians, and physiotherapists.

IMT in patients with CF has been reported to improve endurance and strength of the inspiratory muscles, as well as exercise capacity [5]. Previous research has shown that increases in exercise capacity are associated with the improved psychosocial status in patients with chronic pulmonary disease [22]. In addition, a recent study found that aerobic fitness positively associated with health-related QoL in patients with CF, underlining the importance of good physical fitness [23]. However, whether greater perceived ability to be physically active has the potential to influence psychosocial health and QoL in patients with CF remains unknown.

The perceived improvement in physical ability reported by participants could be attributed to the good adherence to the IMT program. This is in contrast to previous reports that adherence to treatment in CF is suboptimal [24]. This discrepancy could be a result of our participants' MDT, the age of our participants, and the small numbers involved in the study. Adherence levels among patients with CF tend to decline with the increasing age [25]. In younger children, treatment responsibility often lies with parents or guardians, resulting in greater adherence. As adherence was self-reported by participants in this study, it may have been over- or underestimated and is, subsequently, subject to the risk of bias [26]. Key factors that influence adherence include family environment, stigma, embarrassment among peers, and relationship with their MDT [24]. Indeed, the interview findings presented here reflect an MDT that actively encourage patients to make their own choices about treatment decisions and are open to trialing new or novel interventions such as IMT.

With a reduced exercise capacity and low daily PA levels potentially impacting psychological and physiological health of patients with CF, parental and family involvement in PA is extremely important when encouraging children to meet recommended PA and exercise guidelines [27], which can be translated to IMT interventions. Healthy children with physically active parents are over five times more likely to be active than children whose parents are inactive [28], which correlates with reports from the MDT that an active “sporty family” is essential regarding children’s participation levels. In addition, children’s moderate-to-vigorous PA (MVPA) levels have been shown to correlate with their parents’ [29], with family cohesion and parent-child joint PA predicting higher levels of MVPA [30]. Conversely, divorced parents can have a negative impact on a child’s PA levels when the main parental facilitator becomes less involved [31]; this impact of divorced parents was highlighted by the MDT.

In addition to families, peer support is influential in determining activity-related self-esteem and, therefore, treatment behaviors[32]. School-aged children with CF report concerns of appearing “different” than their peers [33], and our participants voiced that they like to keep their condition separate from their friendships at school. This is in accordance with research in which children and adolescents with CF attempted to conceal their disease and symptoms to appear “normal” to their peers [34]. As the perspectives of peers are critical to social acceptance, it is essential that children with CF are not defined by their disease but have their own identity. The time-efficient nature of IMT provides the capacity for self-directed therapy that does not detract from time spent with peers, which may increase adherence.

Despite the ease of implementation, good adherence, and enjoyment reported by participants, the MDT was more reserved with regards to their enthusiasm for an IMT intervention, with reservations relating to cost and treatment burden. Nevertheless, the team expressed an interest in investigating the potential of a longer-term IMT intervention to provide a clearer evidence-base on the impact on psychological and physiological health in patients with CF. The main concern voiced by the care team, as well as children with CF, was the potential burden it may have on patients in terms of their time and current treatments. Reports that a patient with CF can spend a mean of 108 minutes per day on a wide range of CF therapies, regardless of age or disease severity [3], highlights the importance of establishing the feasibility of time-efficient therapies such as IMT. In addition, the CF care team recommended that future IMT interventions incorporate technology, including the ability to monitor adherence objectively to reduce the risk of bias, linking to smartphones and providing visual feedback. With smartphone ownership increasing, its usability for future interventions is highlighted by its accessibility, real-time assessment, adherence monitoring, visual feedback, and adjustability to the user [35]. Increasing patient and MDT engagement in the intervention design has the potential to improve health outcomes, better patient care, and lower costs [36] and, furthermore, is essential in improving the quality of health care and efficacy, which is especially important for the CF population whose treatments are highly prescribed [37].

In conclusion, the data revealed consistent themes relating to IMT among children with CF and their MDT. This preliminary study highlights the ease of incorporating an IMT program into the lives of patients with CF, who reported noticeable perceived improvements to their physical ability after only 4 weeks of IMT. These preliminary results suggest that an IMT intervention may be well accepted by young patients with CF. Furthermore, this study emphasizes the importance of gathering views and opinions of patients and their care teams to ensure good adherence and enjoyment to future interventions.

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Authors' Contributions

MAM and KAM conceived the study, JLM acquired the data, and all authors were involved in the interpretation and manuscript preparation.

Conflicts of Interest

None declared.

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Abbreviations

CF: cystic fibrosis
IMT: inspiratory muscle training
MDT: multidisciplinary team
MVPA: moderate-to-vigorous physical activity
NHS: National Health Service
PA: physical activity
QoL: quality of life

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Fertility Preservation in Children and Adolescents With Cancer: Pilot of a Decision Aid for Parents of Children and Adolescents With Cancer

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Abstract

Background: Future infertility is a significant concern for survivors of childhood and adolescent cancer. Children and adolescents may have the opportunity to undergo fertility preservation (FP) procedures (which preserve gonadal tissue or gametes for future use) prior to the cancer treatment. However, the decision is very complex, as it is often made by parents as proxy decision makers at the time of cancer diagnosis, and is time-sensitive (needing to occur before the cancer treatment begins). Furthermore, FP procedures in children and adolescents are experimental and cannot guarantee future fertility. An uninformed decision may result in future decision regret.

Objective: This study aimed to assess the acceptability, usability, and feasibility of a Web-based FP decision aid (DA) in parents of children and adolescents with cancer and clinicians. Fertility knowledge and decision regret were compared in families who reviewed the DA compared with those who did not.

Methods: The Web-based DA was developed according to the International Patient Decision Aid Standards. A cross-sectional study of parents of patients with cancer, who discussed fertility, and clinicians at a tertiary children’s hospital was undertaken. The acceptability, usability, and feasibility of the DA were assessed using a pre-post survey design. Measures included the validated Decision Regret Scale, a purpose-designed fertility-related knowledge scale, questions regarding satisfaction with the DA, and open-ended responses for additional feedback. Furthermore, clinicians involved in FP were also invited to review the DA.

Results: We enrolled 34 parents and 11 clinicians in this study. Participants who reviewed the DA (15 parents and 11 clinicians) expressed satisfaction with its content and functionality. Parents reported an improved understanding of cancer treatments, infertility, and FP procedures and did not report greater decision regret after DA review. Most parents (13/15, 86%) would recommend the DA to other parents. All clinicians had a consensus that this was a valid and relevant information source for all involved in fertility care.

Conclusions: It is an international standard of care to discuss the impact of cancer treatment on fertility before cancer treatment. This is the first fertility DA for parents of children and adolescents with cancer and is found to be relevant and acceptable by parents and clinicians. This DA has the potential to help support parents to make informed fertility-related decisions for their children and adolescents. However, future research is needed to assess the impact of the DA on prospective decision making.

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KEYWORDS

adolescent; cancer; decision aid; fertility preservation; pediatric; shared decision making; Values Clarification Exercise

Introduction

Australia has one of the highest incidences of childhood cancer worldwide, with >1500 children (0-12 years) and adolescent-young-adult patients (13-25 years) newly diagnosed annually [1,2]. Improvements in care have seen the 5-year survival rate surpass 83%, after which, the lifetime survival is comparable to that of their healthy peers [2,3]. Attention must be given to the late effects of cancer diagnosis and treatment in this growing population of survivors [2].

Common cancer treatments (alkylating chemotherapies and radiotherapy) may have gonadotoxic effects that can damage the reproductive system, resulting in infertility or sterility [4-8]. The risk to fertility is variable and difficult to exactly predict [9,10]. For some patients, this risk is negligible; for others, however, infertility may be almost certain [8,9]. Treatment regimen and dosage, sex, age at diagnosis, pubertal status, and disease are factors that may affect the risk of infertility. Survivors of childhood cancer regard infertility as one of their greatest concerns [7,8,10]. Fertility preservation (FP) procedures may be offered to patients at risk of infertility when medically appropriate [7].

Research regarding the application and efficacy of FP in humans is ongoing [8,11]. Gender and pubertal status determine the availability and accessibility of FP. For females, oocyte and embryo cryopreservation are the most effective means of preserving fertility but not possible in children [7,11]. In addition, ovarian tissue cryopreservation is available, although still considered experimental, with only 130 live births recorded to date [12]. For males, semen cryopreservation is currently the only viable FP procedure available. Preservation of immature testicular tissue is yet to be proven successful in humans [13]. Therefore, ovarian and testicular tissue harvesting procedures are usually only offered to children and adolescents under special governance [8,14].

Many young people are simply too young or feel too overburdened to make the fertility decision themselves and are glad that their parents take the initiative [15,16]. Overall, 48% of young people and 42% of parents experience posttraumatic stress symptoms around the diagnosis. Parental consent for FP decisions is usually required for all children under the age of 18 years (because of vulnerability), with only 33% of boys aged <12 years able to appropriately comprehend fertility information [17]. The importance of parental input is further highlighted that even in young adults (age≤25 years), parents contribute to fertility decisions in 82% of cases. Thus, a large weight of responsibility sits with parents. The potential procedure-related risks, time delays in cancer treatment, and the potential message of false hope regarding cancer survival or the success of FP procedures must be considered [18]. Of concern, is the potential misinterpretation of risks and unrealistic expectations of FP success by patients and their parents [11,18]. The clarification of these factors is of vital importance and may be aided through the provision of balanced and understandable information.

Much of the information regarding FP is new to parents, and the involvement of patients in the decision-making process is variable [8,19]. Patients and families have limited time to consider their options as FP procedures are best undertaken prior to the commencement of gonadotoxic cancer treatments, soon after a cancer diagnosis [8,10]. In addition, there is often no clearly preferable decision, with each FP option having its own inherent risks and benefits that need to be considered with respect to personal values [20]. Thus, the decision to forgo or to pursue FP is difficult, and in this ethically complex scenario, decision makers require decision support.

Decision aids (DA) are educational tools designed to complement clinician counseling and facilitate difficult preference-sensitive decisions [21]. DAs have been shown across a range of health care choices to reduce the decisional conflict (a measure of uncertainty), increase decision satisfaction and knowledge, and minimize future regret, without increasing harm [21]. DAs are now considered to be the “gold standard” approach to shared decision making for complex health care decisions [21,22]. Considering the complexity of FP decision making in the pediatric setting, a DA could provide standardized, evidence-based decision support for parents of pediatric patients with cancer. To the best of our knowledge currently no FP DA is available for use in this clinical setting. Thus, this study aimed to develop and assess the acceptability, usability, and feasibility of a Web-based FP DA for parents of children with cancer who had previously made a fertility discussion as part of their clinical care. In addition, this study compared fertility knowledge and decision regret around their decision in families who reviewed the DA compared with those who did not. Finally, this study aimed to assess the clinician acceptance of the DA by its perceived usefulness and whether they would recommend its use in the clinical practice.

Methods

Participants and Study Design

This study used a cross-sectional pre-post survey design. Parents of patients with cancer (aged 0-18 years) diagnosed between December 2010 and December 2015 at The Royal Children's Hospital, Melbourne, were invited to participate. In addition, clinicians involved in oncofertility (gynecologists, endocrinologists, oncologists, ethicists, pediatric surgeons, and *in vitro* fertilization specialists) were invited to review the DA. All parents had previously discussed their child's fertility with their clinical team. This retrospective study design aimed to minimize the risk to new patients, which is typical for DA pilot studies [9,23]. Ethics approval was obtained from The Royal Children's Hospital Human Research Ethics Committee (36016A).

Participant Population

Parents were eligible for participation if their child's cancer diagnosis occurred within 5 years before December 2015; the child was not on active treatment; they previously had an FP discussion; were proficient in English; and had consented to be contacted for future research. Families where the child was palliative or deceased were excluded. Furthermore, families were excluded if the treating oncologist felt it was clinically inappropriate for them to be contacted for research purposes. The child's risk of infertility was classified as low (<20%), medium (20%-80%), or high (>80%), according to previously published risk tables [9].

Clinician Population

Of 24 invited clinicians, 46% (11/24) consented to participate in this study and completed a post-DA review survey. Of these, 82% (9/11) of the clinicians were involved in FP consultations and were from the disciplines of gynecology, endocrinology, urology, oncology, and clinical ethics.

Procedure

All eligible parents were provided with an invitation pack by the researcher, containing an introductory letter, information sheet, consent form, and pre-DA questionnaire. Once consenting parents (1 parent per family) completed the questionnaire, they were given access to the Web-based DA and the post-DA questionnaire.

Clinicians involved in fertility consultations and oncological care were approached either in person or through email. If clinicians consented, they either met for an informal discussion and completed the survey or reviewed the DA online and completed the survey online.

Data Analysis

Data were analyzed using SPSS V22 (IBM Corp, Armonk, NY, USA). Descriptive statistics (means, ranges, and SDs) were calculated to describe sample characteristics and response rates and to assess DA acceptability. In addition, *t* tests were used to compare normally distributed data. Furthermore, thematic analysis was conducted on open-ended responses.

Decision Aid

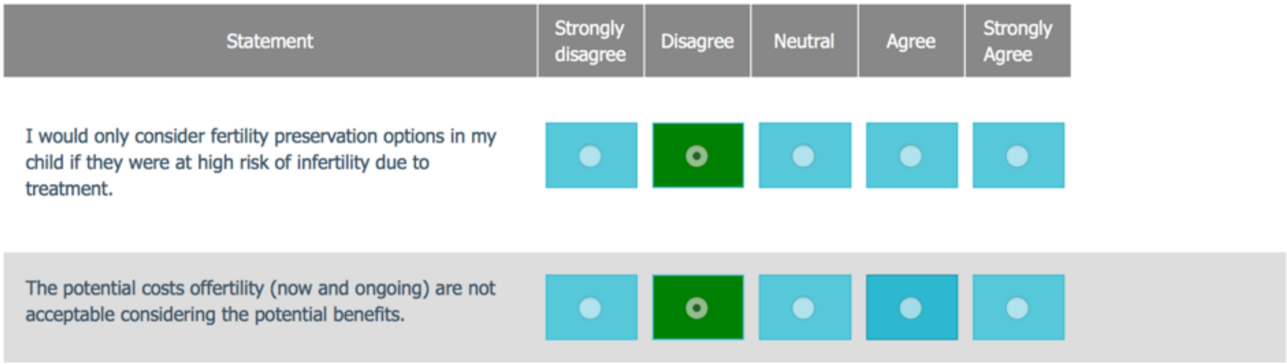
Development of the electronic DA was theoretically guided by Coulter et al [24] and the International Patient Decision Aid Standards, an evidence-based theoretical model for effective behavioral interventions [23,25]. The DA content was informed by two formalized information needs assessments, which were conducted at the Royal Children's Hospital [26,27]; and input from FP Taskforce consumer group. The DA was developed using the WordPress Content Management System (a software application that allows users to design and manage Web-content and materials). The DA has 11 chapters with 22 pages (Multimedia Appendix 1). Where appropriate, content was divided according to the patients' gender. Furthermore, medical illustrations and infographics were included to help quantify the risks of various outcomes and enhance patients' understanding [28].

A novel Web-based Values Clarification Exercise (VCE) was developed for this DA. Questions were designed to help parents clarify the importance of their child's fertility in the context of cancer diagnosis and treatment planning. Parents rated sex- and age-specific statements on a Likert-type scale with responses ranging from "strongly disagree" to "strongly agree." Results were scored from −2 to +2. Higher scores (eg, +2) indicated that fertility was considered a priority, whereas lower scores (eg, −2) indicated that fertility was not a priority; 0 was considered neutral. Figure 1 provides an example of the VCE questions. Parents were provided with a results summary bar (Figure 2), where their mean score represented the priority of FP for the parent and SD represented the variability around that score. The mean VCE score is plotted as a percentage of 100, where "not a priority" ranges from 0% to 33%, "neutral" ranges from 34% to 67%, and "priority" ranges from 68% to 100%. Color spread is calculated using SD, adjusted to a range between 10 and 50 points, and spread from the central score in both directions.

Survey Measures

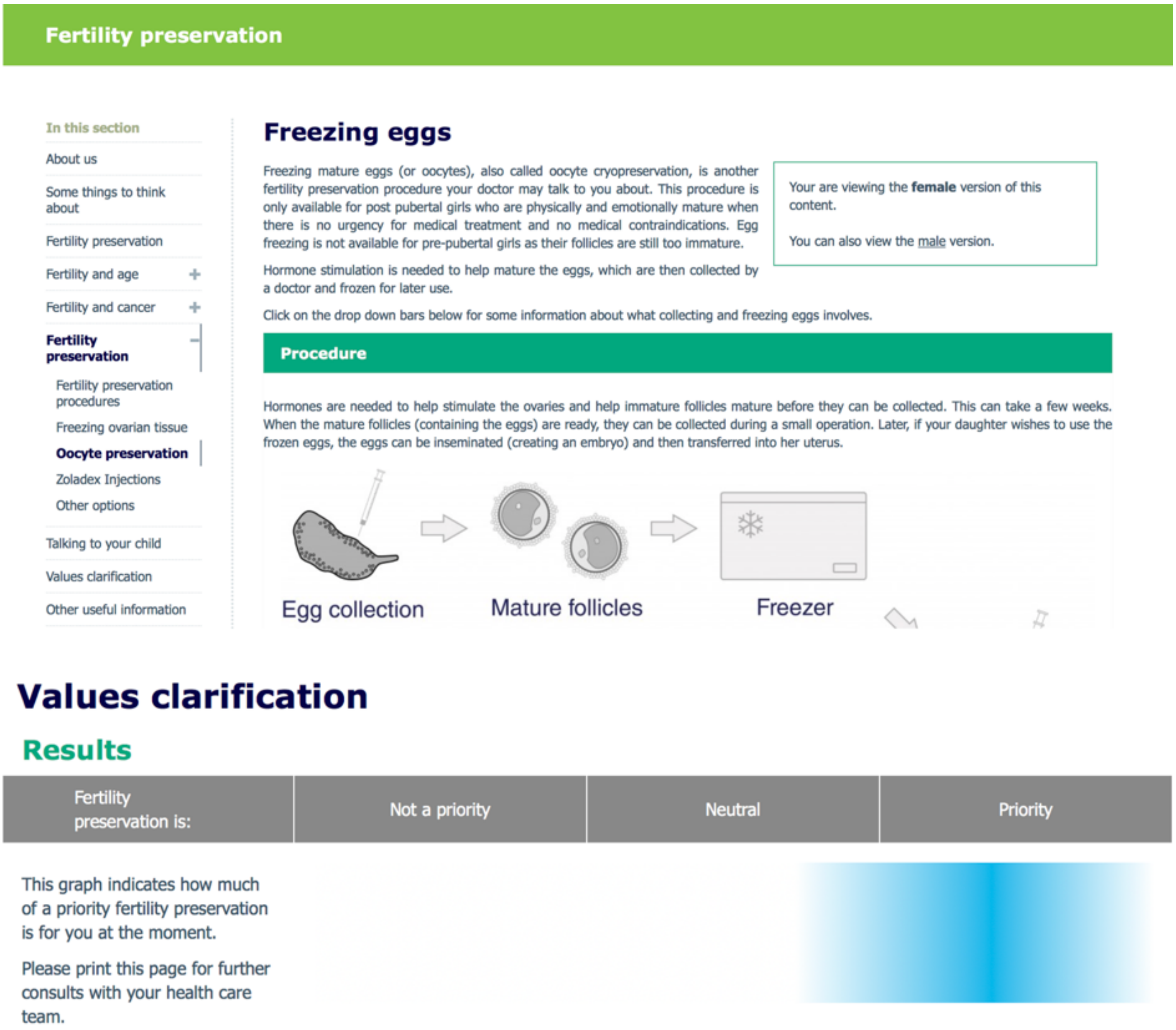
Questionnaires were adapted from those previously used in similar studies [25,29]. Multimedia Appendix 2 outlines the outcome measures assessed. The clinician survey included a question of whether the clinician would recommend the DA to patients and an open-ended question about future improvements and thoughts.

Figure 1. Example questions from the values clarification exercise.



Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree
I would only consider fertility preservation options in my child if they were at high risk of infertility due to treatment.	○	●	○	○	○
The potential costs offertility (now and ongoing) are not acceptable considering the potential benefits.	○	●	○	○	○

Figure 2. Decision aid and values clarification results bar.



Fertility preservation

In this section

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Freezing eggs

Freezing mature eggs (or oocytes), also called oocyte cryopreservation, is another fertility preservation procedure your doctor may talk to you about. This procedure is only available for post pubertal girls who are physically and emotionally mature when there is no urgency for medical treatment and no medical contraindications. Egg freezing is not available for pre-pubertal girls as their follicles are still too immature.

Hormone stimulation is needed to help mature the eggs, which are then collected by a doctor and frozen for later use.

Your are viewing the **female** version of this content.

You can also view the male version.

Click on the drop down bars below for some information about what collecting and freezing eggs involves.

Procedure

Hormones are needed to help stimulate the ovaries and help immature follicles mature before they can be collected. This can take a few weeks. When the mature follicles (containing the eggs) are ready, they can be collected during a small operation. Later, if your daughter wishes to use the frozen eggs, the eggs can be inseminated (creating an embryo) and then transferred into her uterus.

Values clarification

Results

Fertility preservation is:	Not a priority	Neutral	Priority

This graph indicates how much of a priority fertility preservation is for you at the moment.

Please print this page for further consults with your health care team.

Results

Response Rates

In this study, 74 families were eligible for participation. Of these, 34 parents consented to participate and completed the pre-DA questionnaire (survey 1). Then, 19 parents withdrew after completing survey 1, citing time constraints (n=5), or did not respond to follow-up (n=14). Subsequently, 15 parents reviewed the DA and completed the post-DA questionnaire (Figure 3).

Characteristics of Parents Who Reviewed the Decision Aid

The mean age of parents was 43 years. Compared with parents who only completed survey 1 (n=19), those who reviewed the DA (n=15) were more likely to be in part-time or full-time employment and have a higher level of education (Table 1). In addition, the distribution of infertility risk differed markedly between the 2 groups (Table 2). Otherwise, the 2 groups were similar with respect to demographics and concerns around their child’s future fertility.

Decision Aid Assessment and Impact in Those Who Completed Surveys 1 and 2

Satisfaction With Decision Aid Design

Most parents (10/15; 67%) reported reading the DA “quite thoroughly” or “thoroughly from beginning to end,” with a median time of 25 minutes (range 15 to >60 minutes). All parents considered the length to be “about right,” 53% (8/15) reported that the DA was “very appealing” to look at, and 73% (11/15) mentioned that it was “very clearly” presented. In addition, 60% (9/15) parents were satisfied with the website format, while 33% (5/15) said they would also like a booklet, and 1 parent stated they would have liked a video.

Satisfaction With Content

The majority (13/15, 87%) of parents reported that the information in the DA was “balanced and fair,” and 13% (2/15) reported that the DA was in “favor of FP.” Most parents (12/15, 80%) felt that the information was “sufficiently detailed.” One parent found the DA to be confusing, while 87% (13/15) parents reported that it “clearly” or “very clearly” presented their child’s fertility choices. The majority (12/15, 80%) reported that the information would have been “quite” or “very” relevant when considering FP for their child.

Expectations of the Decision Aid

Overall, parents were “satisfied” (11/15, 73%) or “very satisfied” (4/15, 27%) with the DA. One parent, however, reported that the DA would not have helped them cope with their situation. The DA “met” (11/15, 73%) or “exceeded” (4/15, 27%) the expectations of all parents.

Emotional Impact of the Decision Aid

In this study, 47% (7/15) parents reported having “somewhat” thought about the information since reading the DA. In addition, 40% parents (6/15) reported feeling “a little” worried or concerned about the information. Themes emerging from open-ended responses related to concerns regarding future impacts of treatments on fertility with 1 parent commenting that she was “worried for my (child) as preservation was not an option for her” and another commenting that she was “not so much worried I guess, just sad,” indicating that worry was linked to concerns about the future impact of treatments on fertility.

Perceived Usefulness as a Decision-Making Tool

Overall, 86% (13/15) of parents reported that the DA would have been “helpful” or “very helpful” in helping them decide on their child’s treatment in general. In addition, 86% (13/15) reported that it would have been “helpful,” “very helpful,” or “extremely helpful” in making decisions about FP and would recommend the DA to other families facing an FP decision.

Figure 3. Parent participant recruitment flowchart.

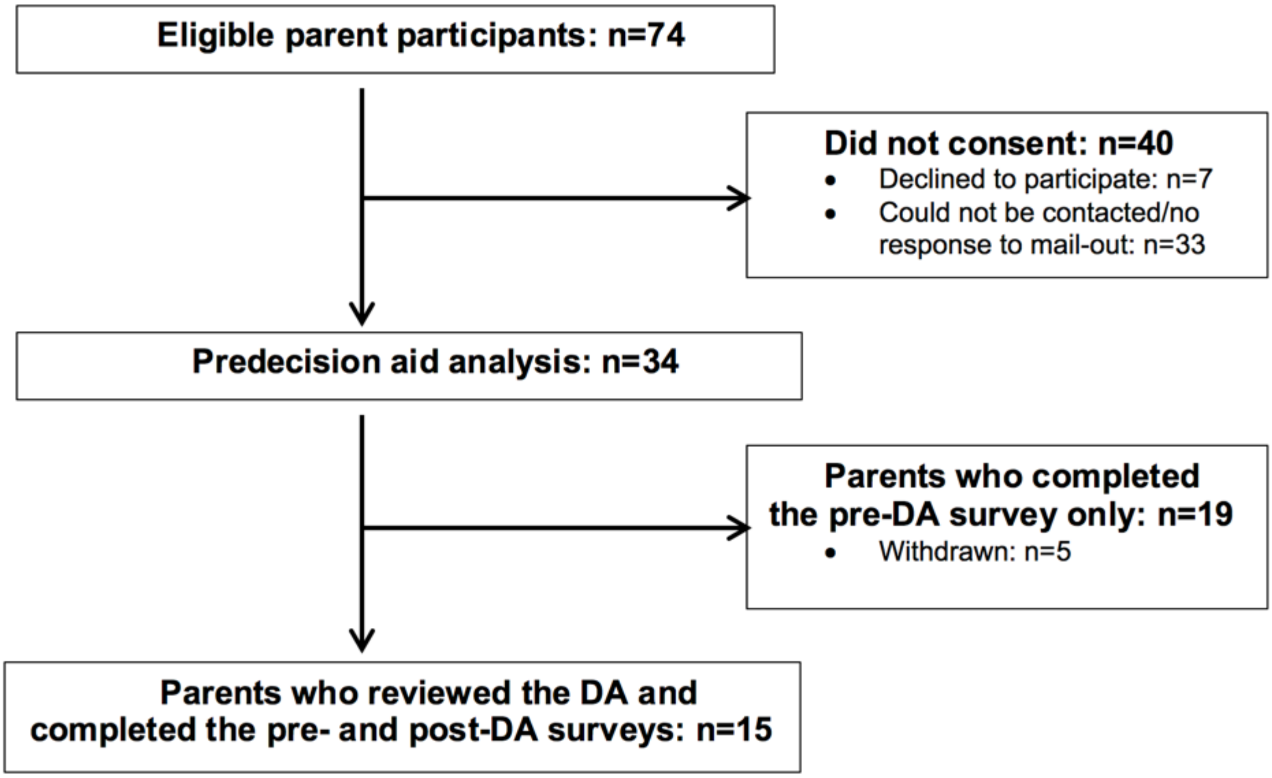


Table 1. Demographic characteristics of parents of children and adolescents with cancer.

Characteristics	Total parents (N=34)	Completed the pre-DA[a] survey only (n=19)	Reviewed the DA and completed the pre- and post-DA surveys (n=15)	*P* value[b]
Age in years, mean (SD); range	41.5 (11.1); 27-57	43.2 (8.1); 27-57	42.6 (7.0); 31-49	.28
Age at child’s diagnosis in years, mean (SD); range	39.3 (11.2); 25-55	40.8 (7.7); 25-55	40.5 (6.7); 30-47	.19
Decision regret score, mean (SD); range	15.6, (20.5); 0-95	16.8 (23.5); 0-95	16.5 (18.6); 0-50	.74
Country of birth, n (%)				
Australia	24 (71)	16 (67)	8 (33)	.84
Other	10 (29)	3 (30)	7 (70)	
Primary spoken language at home, n (%)				
English	29 (85)	18(62)	11(38)	.51
Other	5 (15)	1 (20)	4 (80)	
Relationship status, n (%)				
Married or de facto	25 (74)	12 (48)	13 (52)	.26
Separated or divorced	7 (21)	5 (71)	2 (29)	
Unknown	2 (6)	2 (100)	0 (0)	
Highest level of education, n (%)				
≤Year 10	6 (18)	4 (67)	2 (33)	.04[c]
Year 12	4 (12)	2 (50)	2 (50)	
Technical and Further Education certificate or diploma	4 (12)	3 (75)	1 (25)	
Bachelor’s degree	12 (35)	2 (17)	10 (83)	
Postgraduate degree	7 (21)	7 (100)	0 (0)	
Unknown	1 (3)	1 (100)	0 (0)	
Employment status, n (%)				
Full time	9 (26)	2 (29)	7 (71)	.001[c]
Part time	11 (32)	7 (64)	4 (36)	
Self employed	2 (6)	1 (50)	1 (50)	
Full-time or part-time student	1 (3)	0 (0)	1 (100)	
Unemployed	7 (21)	6 (86)	1 (14)	
Unknown	4 (12)	3 (75)	1 (25)	
Occupation, n (%)				
Professional	15 (44)	6 (40)	9 (60)	.51
Clerk or sales	3 (9)	2 (100)		
Home duties	5 (15)	4 (80)	1 (20)	
Other	11 (32)	7 (64)	4 (36)	
Parity, n (SD); range[d]	2.5 (1.1); 1-6	2.6 (1.4);1-6	2.3 (0.6);1-3	.32
Parents own past conception difficulties, n (%)				
Yes	5 (15)	1 (20)	4 (80)	.50
No	29 (85)	18 (62)	11 (38)	
Concerns regarding their child’s future fertility at diagnosis, n (%)				
Yes	23 (68)	12 (52)	11 (48)	.19
No	8 (24)	5 (63)	3 (37)	
Unsure	3 (9)	2 (67)	1 (33)	

Characteristics	Total parents (N=34)	Completed the pre-DA[a] survey only (n=19)	Reviewed the DA and completed the pre- and post-DA surveys (n=15)	*P* value[b]
Recalled a fertility discussion, n (%)				
Yes	29 (85)	16 (55)	13 (45)	.85
No	5 (15)	3 (60)	2 (40)	
Clinician involved in fertility discussion, n (%)				
Oncologist	12 (35)	7 (58)	5 (42)	.10
Gynecologist	7 (21)	4 (57)	3 (43)	
Oncologist + gynecologist or endocrinologist or nurse	7 (21)	4 (57)	3 (43)	
Endocrinologist	0 (0)	0 (0)	0 (0)	
Nurse	2 (6)	1 (50)	1 (50)	
Social worker	2 (6)	1 (50)	1 (50)	
Unknown	4 (12)	2 (50)	2 (50)	

[a] DA: decision aid.

[b] *t* test (two-tailed) between parents who completed only the pre-DA survey only and those who completed both pre- and post-DA surveys.

[c] Significant at $P \leq .05$.

[d] The number of children the parents of patients have had.

Table 2. Characteristics of childhood and adolescent patients with cancer.

Characteristics	Total children and adolescents (N=34)	Those whose parents completed the pre-DA[a] survey only (n=19)	Those whose parents reviewed the DA and completed the pre-and post-DA surveys (n=15)	*P* value[b]
Age in years, current mean (SD); range	9.9 (6.2); 1.5-19.6	9.9 (6.2); 1.8-19.6	9.3 (6.4); 1.5-19.2	.88
Age at diagnosis in years, mean (SD); range	7.7 (5.9); 1.0-17.2	7.7 (6.0); 1.0-17.2	7.4 (5.9); 1.0-17.2	.58
Pubertal status at diagnosis, n (%)				
Prepubertal	22 (65)	12 (55)	10 (45)	.63
Postpubertal	12 (35)	7 (58)	5 (42)	
Diagnosis, n (%)				
Leukemia	10 (29)	4 (40)	6 (60)	.38
Rhabdomyosarcoma	5 (15)	2 (40)	3 (60)	
Ewing’s Sarcoma	5 (15)	4 (80)	1 (20)	
Central nervous system	3 (9)	2 (67)	1 (33)	
Hodgkin’s Disease	2 (6)	1 (50)	1 (50)	
Osteosarcoma	3 (9)	2 (67)	1 (33)	
Other solid cancers	5 (15)	3 (60)	2 (40)	
Non-Hodgkin’s	1 (3)	1 (100)	0 (0)	
Estimated risk of infertility, n (%)				
Low	5 (15)	1 (20)	4 (80)	.04
Medium	14 (41)	8 (57)	6 (43)	
High	15 (44)	10 (67)	5(33)	
Type of fertility preservation procedures, n (%)				
Ovarian tissue cryopreservation	8 (24)	6 (75)	2 (25)	.68
Ovarian tissue cryopreservation + gonadotropin-releasing hormone agonist + oocytes	2 (6)	1 (50)	1 (50)	
Testicular tissue cryopreservation	10 (29)	5 (50)	5 (50)	
Semen cryopreservation	3 (9)	2 (67)	1 (33)	
No procedure	11 (32)	5 (45)	6 (55)	

[a] DA: decision aid.

[b] *t* test (two-tailed); significant at $P \leq .05$.

Of the 8 parents who completed the VCE, half reported that it would have been “satisfactory” in helping them decide, while the other half reported it would have been “very helpful.” Reasons cited for not completing the VCE included time constraints, that the parent believed it was irrelevant to their situation, or that they had technical issues with the use of the website.

Improvements in Knowledge and Understanding

In this study, 74% (11/15) parents reported that only some of the information was new to them. The remaining parents reported that either “most” (2/15; 13%) or “none” (2/15; 13%) of the information was new to them. Overall, parents reported the DA helped improve their understanding of cancer treatments, infertility, and FP procedures to some degree (Multimedia Appendix 3).

In addition, 14 parents answered the FP knowledge scale pre- and post-DA review. Prior to the review, parents answered an average of 5.21 (SD 1.66; range 1-8) out of 10 FP knowledge questions correctly. Knowledge scores improved by 1.50 to an average of 6.71 correctly answered questions after reviewing the DA (Table 3); this was a significant ($P<.04$) increase in the number of correct responses overall. Prior to reviewing the DA, 21% (3/14) parents scored >70% on the FP knowledge scale; this increased to 64% (9/14) after DA review.

Expectations of the Fertility Preservation

The expectation of the FP success was asked in general, not relating specifically to their child and encompassed all FP procedures, not just experimental procedures. Notably, 11 parents reported their expectations of the future success of FP procedures. The majority “agreed” or “strongly agreed” (8/15; 73%) that FP would be successful in their lifetime. Similarly, 73% (11/15) responded that they “agreed” or “strongly agreed” that FP will be successful within the lifetime of their child. This decreased to 46% (7/15) after DA review. The change in expectations varied between parents of boys and girls (Figure 4). Expectations of success in this lifetime decreased in parents of boys and increased in parents of girls. Conversely, expectations of success in the next generation increased for parents of boys and decreased in girls.

Decision Regret

In this study, 14 parents completed the Decision Regret Scale (Table 3). The mean regret score pre-DA review was 16.5 (SD 18.6; range 0-50), and post-DA review was 18.5 (SD 19.4; range 0-50). There was a nonsignificant increase in scores across all parents of 1.9 points (4.2-point increase in parents of boys and 0 in parents of girls; *P*=.52).

Clinician Review of the Decision Aid

Usability and Content Usefulness and Satisfaction of the Decision Aid Design

All clinicians reported that they would recommend the DA to patients. When asked for their thoughts on the DA, three main themes emerged from the comments: (1) the DA was well designed and easy to use; (2) the DA was a good information source; and (3) there is a need for more information and resources for patients and parents beyond the DA.

Design, Usability, and Content

Clinicians reported satisfaction with the design and usability of the DA website, commenting that it was an "excellent and well-structured" resource. In addition, the DA was regarded as a valid and relevant source of information for clinicians, patients, and their families with one clinician commenting that "I found it useful as a resource prior to meeting with a patient."

Perceived Need for Information and Patient Resources

In this study, 36% (4/11) of the interviewed clinicians highlighted a lack of patient and parent resources regarding infertility, FP procedures, and processes. One clinician commented that she had "observed more and more adolescents, especially boys" making FP decisions, noting that there are very few resources tailored toward adolescents and parents of adolescents.

Table 3. Change in the parental fertility preservation-related knowledge and decision regret pre- and postdecision aid (n=15).

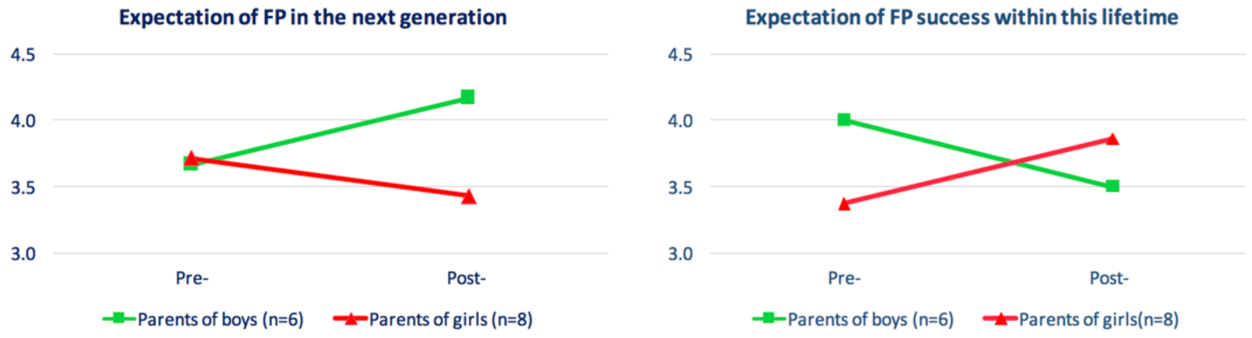
Change	Pre-DA[a] mean score (SD); range	Post-DA mean score (SD); range	Mean change score	SE	95% CI	*t* [b]	Degree of freedom	*P* value
Fertility preservation knowledge								
All parents (n=14)	5.21 (1.66); 1-8	6.71 (1.94); 3-10	1.50	0.66	0.07 to 2.93	2.27	13	.04[c]
Parents of boys (n=6)	5.17 (1.46); 4-8	6.33 (2.13); 3-10	1.17	1.20	0.19 to 1.90	0.98	5	.37
Parents of girls (n=8)	5.25 (1.79); 1-7	7 (1.73); 4-10	1.75	0.80	0.13 to 3.63	2.20	7	.06
Decision regret scale scores								
All parents (n=14)	16.5 (18.6); 0-50	18.5 (19.4); 0-50	1.9	5.17	–9.51 to 4.67	0.64	13	.54
Parents of boys (n=6)	5.8 (12.0); 0-30	10.0 (16.7); 0-40	4.2	3.75	–13.79 to 5.46	1.11	5	.32
Parents of girls (n=8)	25.7 (19.0); 0-50	25.7 (19.7); 0-50	0	4.76	–11.64 to 11.64	0.00	7	1.0

[a] DA: decision aid.

[b] *t* test (two-tailed).

[c] Significant at *P*≤.05.

Figure 4. Parents' expectations of fertility preservation success within this lifetime and the lifetime of the next generation. FP: fertility preservation; 5: Strongly agree; 4: Agree; 3: Neither agree nor disagree; 2: Disagree; 1: Strongly disagree.



Discussion

In this pilot study, we evaluated the parental and clinical acceptance of the first FP DA for parents of children and adolescents with cancer. Our data suggest that the DA was acceptable, did not increase parental concern, and would be useful for parents making an FP decision. Furthermore, initial testing suggests the DA increases FP-related knowledge. Parents and clinicians would recommend this tool to others faced with a similar decision. However, we acknowledge the high dropout in this study. These results support further formal evaluation of the DA in a larger prospective trial, prior to the implementation of the DA as a decision-support tool in clinical practice.

The DA was positively received by parents who viewed it. Parents felt that the DA provided unbiased information in an easy-to-read format and was relevant to their situation. Of note, 13% (2/15) parents felt that the DA favored FP. The theoretical framework behind DA development is that it should not favor a particular option but provide a balanced view so that users can make fair decisions [21]. Most of the cohort had undergone an FP procedure, and our DA presented a large amount of information concerning FP procedure outcomes, which may have contributed to the impression of some parents that it favored FP.

One of the primary purposes of our DA was to increase parents' fertility-related knowledge scores in parents despite parents already having experience with FP. These results should be interpreted cautiously because of small numbers. However, in parents with no or little FP awareness, we hope there would be a more significant impact on knowledge, as has been demonstrated in other health-related DA studies [21,29].

A key component of informed decision making is an understanding of the likelihood of the possible outcomes and the associated risks and benefits [13]. Interestingly, post-DA review parents' expectations of FP had changed. Expectations of the success of experimental procedures "in this lifetime" decreased for parents of boys and increased for parents of girls; this change may reflect a better understanding of the technologies as they currently stand, considering that ovarian tissue cryopreservation is being used to achieve pregnancy, but testicular tissue cryopreservation has not yet been successfully used in humans. That parents had perhaps more realistic expectations of FP is important in that (1) they may have a more accurate perception of the risks and likely future successes of FP; (2) that improved perception may lead to better-quality decision making, thereby decreasing the risk of future decision regret; and (3) there may be scope for this DA to improve informed consent in clinical practice.

The DA had an emotional impact on some parents, with 40% (6/15) reporting feeling "a little" worried or concerned after reviewing the DA; this was somewhat expected as the DA was a comprehensive fertility resource and the additional information may have raised issues that were not previously discussed with parents at the time of decision making or may have since been forgotten. One participant stated that the information in the DA gave them a more realistic understanding of their child's fertility risk; this highlights the importance of ensuring that parents are well informed at the time of diagnosis and receive adequate fertility counseling during their posttreatment care [30].

The DA did not increase decision regret in parents; this may reflect that the DA confirmed that parents made the right decision. Ultimately, it does not appear that the DA increases distress, and thus, it is likely to be suitable for use in parents of newly diagnosed children adolescents. Notably, decision regret was measured shortly after DA review. While it was not evident at that time, it is possible that regret may increase months or years later [31], depending on the state of reproductive technologies when the patient wishes to conceive; this has yet to be explored and is an area for further research.

A novel feature of this DA is the rapid feedback provided through the Web-based VCE, which provided a visual representation of the importance of FP to participants, based on the responses provided to a series of questions. To the best of our knowledge, this is the first report of a VCE that functions in this way. All parents who completed the VCE reported that it would have been helpful to some extent when making the decision. Although our data did not provide the information to ascertain whether this was a result of the ease of the click-through VCE, the visual result, or both, it does suggest that a Web-based tool may have merit. Although these data are positive, only 53% (8/15) completed the VCE. Reasons for noncompletion included time constraints, inaccessibility, and unclear instructions. A post-hoc consumer review revealed that the link name for the VCE was confusing. Other studies have reported varying rates of the VCE completion in pilot studies and suggest that what is reported in pilot studies is not reflective of what happens in prospective studies [32]; thus, prospective evaluation is needed.

Although our findings support the utility of a fertility DA for parents of children and adolescents with cancer, our study had inherent limitations. As with most small samples, care must be taken with interpretation of results, as they may not be generalizable. Parents were asked to reflect on their FP decision-making process, which could have been up to 5 years previously. It was not possible to capture the lived experience, and parents may have been biased by intervening events. In addition, study measures were limited by a retrospective sample. Therefore, it was not possible to measure the decisional conflict, a measure of uncertainty and a key factor affecting decision making [33]. However, this study design is an appropriate and necessary way to assess DA acceptability and usability prior to prospective evaluation.

Dropout in this study was higher than expected, resulting in a small sample size. While parents indicated they were keen to participate, many noted that the high time demands of the study and had limited time to engage in a detailed review of the DA. It is likely that in a study of parents making prospective decisions in real time, a higher proportion of parents would wish to actively review the DA. Previous pilot DA studies have shown similar sample sizes to be sufficient to test acceptability and usability of the tools prior to prospective evaluation [32,34].

Overall, clinicians reported satisfaction with the DA design and most importantly would recommend the DA to parents facing a fertility-preservation decision. The resource was regarded as valid and relevant, and interestingly was “a useful resource prior to meeting with a patient.” Research has shown that even with the best intentions, clinicians struggle to convey information and potential risks to patients in language that is easily comprehensible [14]. In the future, this plain language resource could be used to support clinician education and potentially improve fertility-preservation counseling. Lastly, clinicians reported a lack of resources to support children and adolescents in the shared decision-making process. Perhaps the development of an adolescent and young adult FP DA or toolkit may address this gap.

There is a growing body of evidence highlighting the importance of information provision regarding the risks to fertility from cancer treatments and potential FP options. Information provision is important at the time of diagnosis prior to treatment and the potential harm to reproductive tissues [8]. Information regarding cancer treatments, fertility, and potential FP procedures is complex and may be difficult to comprehend [35], especially given the stress of a new cancer diagnosis and the short timeframes in which patients and their parents are required to make decisions. This DA is acceptable and relevant to parents and may assist families who are actively engaged in making an FP decision. Results warrant evaluation in prospective studies, which can assess outcome measures such as decisional conflict as well as decision regret.

As the health care user and provision landscape are rapidly changing, it is increasingly important for health care tools to evolve to further improve patients’ interactions with health care systems, clinical teams, and improve participation and satisfaction with shared decisions. This novel study has developed and preliminarily assessed the first, Web-based FP DA for parents of children and adolescents with cancer. This research has shown the DA to be acceptable to parents who have previously made an FP decision for their children and adolescents with cancer without causing distress. This study adds to the growing pool of research regarding pediatric FP, DA evaluation, and parental (proxy) decision making.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Fertility decision aid content.
[PDF File (Adobe PDF File), 24KB - pediatrics_v1i2e10463_app1.pdf]

Multimedia Appendix 2
Pre- and postdecision aid survey measures.
[PDF File (Adobe PDF File), 43KB - pediatrics_v1i2e10463_app2.pdf]

Multimedia Appendix 3
Improved understanding of fertility preservation in parents’ postdecision aid review; n=15 (%).
[PDF File (Adobe PDF File), 33KB - pediatrics_v1i2e10463_app3.pdf]

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Abbreviations

DA: decision aid
FP: fertility preservation
VCE: Values Clarification Exercise

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Original Paper

Assessing the Usability of an Automated Continuous Temperature Monitoring Device (iThermonitor) in Pediatric Patients: Non-Randomized Pilot Study

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Abstract

Background: Fever is an important vital sign and often the first one to be assessed in a sick child. In acutely ill children, caregivers are expected to monitor a child’s body temperature at home after an initial medical consult. Fever literacy of many caregivers is known to be poor, leading to fever phobia. In children with a serious illness, the responsibility of periodically monitoring temperature can add substantially to the already stressful experience of caring for a sick child.

Objective: The objective of this pilot study was to assess the feasibility of using the iThermonitor, an automated temperature measurement device, for continuous temperature monitoring in postoperative and postchemotherapy pediatric patients.

Methods: We recruited 25 patient-caregiver dyads from the Pediatric Surgery Department at the Massachusetts General Hospital (MGH) and the Pediatric Cancer Centers at the MGH and the Dana Farber Cancer Institute. Enrolled dyads were asked to use the iThermonitor device for continuous temperature monitoring over a 2-week period. Surveys were administered to caregivers at enrollment and at study closeout. Caregivers were also asked to complete a daily event-monitoring log. The Generalized Anxiety Disorder-7 item questionnaire was also used to assess caregiver anxiety at enrollment and closeout.

Results: Overall, 19 participant dyads completed the study. All 19 caregivers reported to have viewed temperature data on the study-provided iPad tablet at least once per day, and more than a third caregivers did so six or more times per day. Of all participants, 74% (14/19) reported experiencing an out-of-range temperature alert at least once during the study. Majority of caregivers reported that it was easy to learn how to use the device and that they felt confident about monitoring their child’s temperature with it. Only 21% (4/9) of caregivers reported concurrently using a device other than the iThermonitor to monitor their child’s temperature during the study. Continuous temperature monitoring was not associated with an increase in caregiver anxiety.

Conclusions: The study results reveal that the iThermonitor is a highly feasible and easy-to-use device for continuous temperature monitoring in pediatric oncology and surgery patients.

Trial Registration: ClinicalTrials.gov NCT02410252; https://clinicaltrials.gov/ct2/show/NCT02410252 (Archived by WebCite at http://www.webcitation.org/73LnO7hel)

(JMIR Pediatr Parent 2018;1(2):e10804) doi:10.2196/10804

KEYWORDS

connected health; continuous monitoring; mobile phone; pediatric; temperature

Introduction

Critical pediatric illness can be a major source of stress for parents. Fever is a common symptom in postoperative pediatric patients as well as in those with neutropenia [1,2]. Even though most fevers within 48 hours of a surgery are benign and self-limiting, fever can be a sign of underlying complication and parents are expected to be vigilant [1,3]. Furthermore, pediatric patients with cancer undergoing chemotherapy are predisposed to infectious complications because of neutropenia induced by myelosuppressive therapy and require caregivers to be watchful for even longer periods of time [3,4]. In both cases, fever is the first clinical sign of infection, and early detection is essential to evaluate the risk for further complications and death [4,5]. Therefore, continued monitoring of body temperature may be helpful in detecting any sudden changes in body temperature that may be related to a significant cause of illness in children [4].

Furthermore, monitoring a child periodically for fever can add to the already stressful experience of taking care of a sick child, leading to fever phobia, a well-documented phenomenon in parents [6]. Moreover, previous studies show that parental knowledge about normal body temperature and the temperature that indicates fever is often poor, and few parents can accurately take temperature measurements [7-9]. Even in parents who do not belong to any of these groups, the process of monitoring fever periodically can be significantly disruptive to daily routine and necessitate interruption of sleep. Thus, automated and continuous fever monitoring for children can overcome several problems described above.

The iThermonitor is a continuous temperature-monitoring device that can transmit temperature data to a mobile phone app paired with the device. However, the availability of this novel technology may not necessarily translate into its adoption due to parental concerns and low receptivity toward new technology. The primary aim of this study was to evaluate the feasibility of using a US Food and Drug Administration-approved automated device for continuous temperature monitoring in postoperative and postchemotherapy pediatric patients. We also evaluated the usability, satisfaction, and engagement of caregivers with the device. Finally, we assessed whether continuous temperature monitoring inadvertently increased caregiver anxiety.

Methods

Study Objective

We conducted a pilot study to evaluate the feasibility of using the iThermonitor for continuous temperature monitoring in postoperative and postchemotherapy pediatric patients.

Recruitment and Study Procedures

Formal enrollment in the study occurred during an in-person enrollment visit scheduled with patients and caregivers. At the enrollment visit, after explaining study details and procedures, pediatric participants and their caregivers were given sufficient time to review the consent form and encouraged to ask questions. Caregivers consented to the study on behalf of pediatric participants and were asked to complete the enrollment questionnaire. Pediatric participants aged 10-17 years were also required to confirm their willingness to participate in the study by signing an assent form. An informed consent form was signed and collected prior to the study. The enrollment questionnaire was administered after obtaining informed consent, which contained questions on demographic information, caregiver technology use, and Generalized Anxiety Disorder-7 questionnaire (GAD-7; Multimedia Appendices 1 and 2). Each day, pediatric participants were asked to wear the device while caregivers were asked to complete an “event-monitoring log” every day over the study period of 14 days (Multimedia Appendix 3). Participants were given instructions to attach the iThermonitor to the skin using a hydrogel dressing that can be changed as needed. Temperature data collected by the iThermonitor were automatically uploaded to a paired receiver (an iPad Mini tablet computer) within a range of 5 m for cloud storage. The provided iPad Mini was preloaded with the iThermonitor app that was used to pair the receiver with the iThermonitor device.

Temperature data were then downloaded and stored in the Partners Healthcare network files. Data files were available to only the Partners Institutional Review Board-approved study staff at Partners Connected Health. If participants required hospital admission, they were asked to stop using the device during their hospital stay. If such a stay resulted in <50% of data being collected, participants were administratively dropped from the study. All participants were asked to continue to receive medical treatment and adhere to other management protocols as recommended by their physicians. After 14 days of use, participants were either scheduled for a closeout visit to return the devices and complete the closeout questionnaire (Multimedia Appendices 2 and 4, respectively) or were sent an electronic questionnaire via Research Electronic Data Capture (an electronic study data capture system) along with shipping material to return their study devices.

Intervention

The iThermonitor (Figure 1) is a US Food and Drug Administration class II device that continuously captures body temperature and automatically delivers the data wirelessly (via Bluetooth or Wi-Fi) to mobile devices or for cloud storage. In addition, it generates and delivers out-of-range temperature alerts on a mobile app for caregivers or providers, allowing them to remotely monitor their child’s temperature (Multimedia Appendix 5).

Figure 1. iThermonitor device.

Data Collection

Feasibility of using the iThermonitor was the primary outcome of interest. Success as a feasible continuous temperature-monitoring tool was defined *a priori* as "80% of the participants viewing the temperature data on the device for at least 80% of the study period." This was assessed in two ways:

- Participant responses from the "event-monitoring log."
- Participant responses to the checklist administered as part of the closeout questionnaire (See below).

> *Please indicate Yes or No for each column every day during the study in response to the following two questions:*
>
> *The iThermonitor stayed on the body for most of the day?*
>
> *I was able to view the temperature data on the iPad mini?*

Secondary outcomes were assessed using a closeout survey designed by study investigators to obtain caregiver feedback about the following: (1) Frequency of receiving out-of-range temperature alerts; (2) Usability of the device; (3) Acceptability of the device; and (4) Caregiver satisfaction in using the iThermonitor. These surveys were administered as part of the closeout questionnaire. Finally, GAD-7 was also administered as part of the enrollment and closeout surveys to assess change in caregiver anxiety levels [10].

Statistical Analysis

We used descriptive statistics to characterize the study sample and survey responses. GAD-7 scores were coded as a categorical variable as follows: mild anxiety (total score 0-5) and moderate or severe anxiety (total score 6-15) [10]. The proportion of participants with mild and moderate or severe anxiety at enrollment and closeout was compared using Cochran's Q test. All analyses were conducted using STATA (StataCorp LLC, College Station TX 77845, USA) version 14.2 with an alpha of .05 set *a priori*. Because this was an exploratory study with descriptive statistics, a complete case analysis approach was adopted for this study.

Sample Size

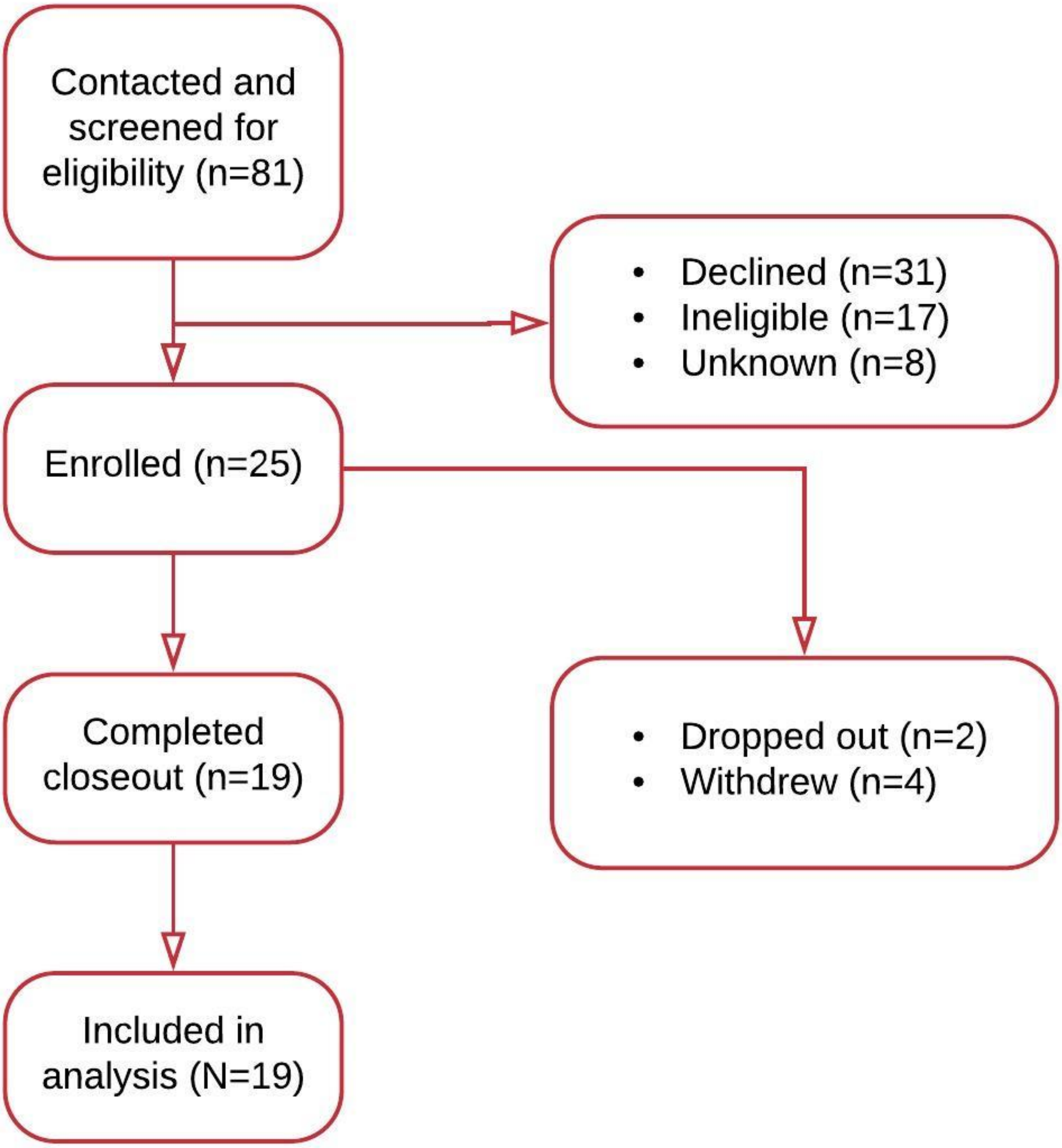
Because this was a pilot study, we did not conduct formal power calculations for sample size estimations. Previous usability studies recommend a sample size of 20 users, which will identify at least 95% of usability problems [11]. We assumed a 20% loss to follow-up rate and arrived at a sample size of 25 patient-caregiver dyads.

Results

Participant Recruitment

We recruited a total of 25 patient-caregiver dyads. The first study participant was enrolled on April 24, 2015, from the MGH Department of Pediatric Oncology, and subsequently, a total of 17 participants were enrolled from this department over a period of >18 months. The first participant from the MGH Department of Pediatric Surgery site was recruited on December 23, 2016, and a total of 8 participants were enrolled, with enrollment completion on February 2, 2017. Figure 2 provides details of participant selection.

Figure 2. Participant enrollment flowchart.



Participant Characteristics

The mean age of participants was 8 (SD 5) years (Table 1). Of the 25 enrolled participants, 4 withdrew consent during the study and 2 were administratively dropped out. Overall, 19 participants completed the study and were included in this analysis. Of all, 94% (17/19) participants identified themselves as white, and 3 out of 4 participants were male (Table 1). The mean age of caregivers was 41 (range, 28-54) years. In addition, 1 in 2 caregivers were employed, 1 in 3 were homemakers, and the rest were unemployed. Furthermore, 63% (12/19) of study participants were pediatric oncology patients, with hematological malignancy being the most common diagnosis (Table 1). Surgical procedures varied widely among the 8 participants, with hernia repair being the only reoccurring procedure.

Table 1. Participant characteristics (N=19).

Characteristics	Value
Male, n (%)	14 (74)
Age of participants in years, mean (SD)	9 (6)
Age of caregivers in years, mean (SD)	41 (8)
Race, n (%)	
White	17 (94)
Asian	1 (6)
Employment status of caregivers, n (%)	
Employed full-time	5 (26)
Employed part-time	3 (16)
Homemaker	6 (32)
Unemployed	5 (26)
Baseline conditions, n (%)	
Malignancies	12 (63)
Hematologic	9 (47)
Intracranial tumor	1 (5)
Rhabdomyosarcoma	1 (5)
Osteosarcoma	1 (5)
Surgical procedures	7 (37)
Hernia repair	2 (11)
Circumcision	1 (5)
Laparoscopy	1 (5)
Orchiopexy	1 (5)
Foreign body removal	1 (5)
Unknown	1 (5)

Attitudes Toward Technology

Most caregivers reported favorable attitudes toward technology. All caregivers reported owning smartphones and using them to access the internet, send or receive emails and short message service text messages, and share pictures. However, only two-thirds of caregivers reported using smartphones or other technology to track weight, diet, or exercise, and only one-third reported using any technology to track health.

Feasibility

In response to the single-item question, all caregivers indicated viewing temperature data on the iPad at least once every day (Figure 3). Majority (5/6, 84%) of caregivers of pediatric surgery patients reported viewing temperature data at least once daily. In comparison, most caregivers of pediatric oncology patients reported viewing temperature data for six or more times per day. However, only 37% (7/19) participants completed the daily event-monitoring log for 12 out of the 14 days, that is, for >80% of the study duration. Furthermore, 100% (19/19) of these participants reported that they viewed temperature data for each of the 12 days.

Figure 3. Frequency of viewing temperature on iPad.

Out-of-Range Temperature Alerts

In this study, 74% (14/19) of caregivers reported receiving an out-of-range temperature alert at least once during the study period. Of these, 64% (9/14) of caregivers reported receiving an alert ≥3 times.

Usability, Acceptability, and Satisfaction

All caregivers reported that it was easy to learn to use the iThermonitor. While 84% (16/19) of caregivers reported feeling comfortable using the device to monitor their child's temperature, 79% (15/19) reported that they could easily monitor their child's temperature with it.

Furthermore, 74% (14/19) of caregivers reported finding the mobile app very useful in monitoring temperature. However, only 53% (10/19) found the out-of-range feature useful. While 74% (14/19) of caregivers reported feeling more confident about monitoring their child's temperature using the device, 79% (15/19) reported that they would recommend it to a friend or a family member. Only 21% (4/19) of caregivers reported that they used another device to monitor the child's temperature during the study.

None of the caregivers reported experiencing problems with the primary function of the device, that is, measurement of temperature. Some caregivers (n=3) had concerns about the minor differences in the temperature reported by the device compared with another thermometer used by them. Most problems reported by caregivers were related to the nonclinical features of the device. For example, few caregivers (n=3) found wireless range of the device to be limited; some (n=5) found it difficult to sync the mobile app with the device. Some caregivers (n=4) occasionally experienced problems with attaching the tape to the child's body or keeping it in place, and others (n=3) found low battery life of the iThermonitor to be bothersome.

Caregiver Anxiety

While 16% (3/19) of participants had mild anxiety, 21% (4/19) had moderate or severe anxiety at enrollment. At closeout, 11% (2/19) participants had mild anxiety and 5% (1/19) had moderate or severe anxiety. However, this difference in proportions was not statistically significant (P=.29).

Discussion

Principal Findings

We conducted a pilot study to evaluate the feasibility of using the iThermonitor as a home-based, continuous temperature-monitoring tool in postoperative and postchemotherapy pediatric patients. The iThermonitor may be a feasible tool to replace conventional temperature monitoring in pediatric patients. Caregivers reported that it was easy to use and increased their confidence in monitoring the child's temperature. Our findings demonstrated that caregivers are willing to engage with continuous temperature-monitoring devices, without experiencing an increase in anxiety. This finding is important considering the well-documented phenomenon of fever phobia [5].

We used two methods for measurement of feasibility: self-reported response in the closeout questionnaire and daily event-monitoring log. The estimates of feasibility of using the device obtained using the self-reported response (16/19, 84%) were substantially higher than those obtained through the daily event-monitoring log (7/19, 37%). The lower estimate of feasibility from the event-monitoring log is likely an artifact of the added burden on study participants to complete one log for each day of participation in the study. In contrast, the burden of participation in the one-time, self-reported response in the closeout questionnaire was much lower. Therefore, despite the possibility of response bias involved with the self-reported questionnaire, it is likely to be a better estimator of feasibility in this study.

Fever is one of the first and most common complications in pediatric surgical patients [12]. Discharge instructions for caregivers often require them to monitor body temperature and take definitive action if it crosses a threshold [9]. However, fever literacy in caregivers has been reported to be low in previous studies [13]. A systematic review of the literature concluded that parental knowledge about body temperature monitoring is poor [7]. Parents have been reported to base their fever management practices on inaccurate temperature readings [7]. Pediatric illnesses are associated with substantial stress experienced by caregivers, and some studies have also reported that parents worry about failing to recognize a serious problem in their acutely sick child [14]. The ability of the caregiver to stay at home with the child and monitor vital signs such as temperature can vary by socioeconomic factors such as education, literacy, income, and marital status [15]. The stress resulting from these factors is only compounded in caregivers of pediatric patients who have a serious illness that requires surgery or prolonged medical treatment [16,17].

Digital health technologies are particularly well suited to eliminate human error from relatively simple tasks in home-based caregiving such as body temperature measurement [18]. These technologies also offer an easy, safe, and comfortable method to monitor body temperature in pediatric patients [5]. In addition, digital health technologies such as the iThermonitor provide a unique opportunity to caregivers to access important data (temperature readings) through the convenience of a phone or tablet computer, thereby eliminating the burden of constant temperature monitoring by caregivers. Furthermore, the out-of-range temperature alerts feature may help reduce caregivers' stress by bringing their attention to any unwanted changes in body temperature.

Limitations

One major limitation of this study is the lack of a control group that used a regular device for temperature measurement such as a digital thermometer without a companion app or automated temperature measurement features. Therefore, we are unable to ascertain the benefit of these features relative to a simple digital thermometer. However, this feasibility pilot study can set the stage for a larger trial to compare clinical and other patient-reported outcomes in patients. Second, we evaluated caregiver engagement through self-reported data at closeout, and thus, these results may be subject to recall bias. Third, parental perception of the novelty of the device may have biased them to provide more favorable responses to the usability and satisfaction assessment. Finally, our study sample represents a relatively narrow selection of pediatric illnesses. Therefore, our findings may not hold true in other pediatric illnesses and in the general population. Hence, a larger sample size is required to evaluate the long-term impact of such continuous monitoring devices.

Conclusion

Overall, the iThermonitor is an easy-to-use device that is highly feasible for continuous monitoring of temperature in pediatric oncology and surgery patients. Most parents quickly developed sufficient confidence in the device to not use any other temperature-monitoring device during the study. Although findings from this pilot study have limited generalizability, a device such as the iThermonitor may have the potential to reduce caregiver stress resulting from taking care of a sick child around the clock. Finally, it may also improve caregivers' knowledge on temperature fluctuations and help them better monitor their children.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
iThermonitor Enrollment Questionnaire.
[PDF File (Adobe PDF File), 211KB - pediatrics_v1i2e10804_app1.pdf]

Multimedia Appendix 2
GAD-7.
[PDF File (Adobe PDF File), 131KB - pediatrics_v1i2e10804_app2.pdf]

Multimedia Appendix 3
iThermonitor Daily Event Monitoring Log.
[PDF File (Adobe PDF File), 26KB - pediatrics_v1i2e10804_app3.pdf]

Multimedia Appendix 4
iThermonitor Closeout Questionnaire.
[PDF File (Adobe PDF File), 246KB - pediatrics_v1i2e10804_app4.pdf]

Multimedia Appendix 5
User Manual.
[PDF File (Adobe PDF File), 248KB - pediatrics_v1i2e10804_app5.pdf]

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Abbreviations

DFCI: Dana Farber Cancer Institute
GAD-7: Generalized Anxiety Disorder Questionnaire
MGH: Massachusetts General Hospital

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Original Paper

Substance Use Among Young Mothers: An Analysis of Facebook Posts

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Abstract

Background: Substance use among young pregnant women is a common and significant public health concern associated with a number of adverse outcomes for both mothers and infants. Social media posts by young women can provide valuable, real-world insight into their perceptions of substance use immediately before and during pregnancy.

Objective: The aim of this study was to characterize the frequency and content of posts regarding substance use in the year before pregnancy and during pregnancy among young mothers.

Methods: Facebook posts were mined from young pregnant women (age, 16-24 years) who consented from 2 Midwest primary care clinics that serve a predominantly low-income community. Natural language processing was used to identify posts related to substance use by keyword searching (eg, drunk, drugs, pot, and meth). Using mixed-methods techniques, 2 investigators iteratively coded and identified major themes around substance use from these mined Facebook posts. Outcome measures include the frequency of posts and major themes expressed regarding substance use before and during pregnancy.

Results: Women in our sample (N=43) had a mean age of 21 (SD 2.3) years, and the largest subgroup (21/43, 49%) identified as non-Hispanic black; 26% (11/43) identified as non-Hispanic white; 16% (7/43) as Hispanic; and 9% (4/43) as non-Hispanic mixed race, Native American, or other. The largest subgroup (20/43, 47%) graduated high school without further education, while 30% (13/43) completed only some high school and 23% (10/43) completed at least some postsecondary education. Young women discussed substance use on social media before and during pregnancy, although compared with the year before pregnancy, the average frequency of substance-related posts during pregnancy decreased. Themes identified included craving alcohol or marijuana, social use of alcohol or marijuana, reasons for abstaining from substance use, and intoxication.

Conclusions: Facebook posts reveal that young pregnant women discuss the use of substances, predominantly alcohol and marijuana. Future work can explore clinical opportunities to prevent and treat substance use before and during pregnancy among young, at-risk mothers.

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KEYWORDS

adolescents; Facebook; mobile phone; pregnant; substance use; social media

Introduction

Substance use among young pregnant women is common and a significant public health concern. While pregnancy is associated with significant reductions in alcohol, cigarettes, and other drug use, both alcohol and illicit drug use remain frequent problems during pregnancy. National surveys reveal that among women aged 15-44 years who are early in their pregnancy, 16.5% report alcohol use in the past month, 10.8% report heavy episodic drinking (ie, binge drinking; ≥4 drinks in a row), and 11.5% report illicit drug use. Compared with young adult and adult women, adolescent women report the highest rates of illicit drug use during pregnancy [1].

The American College of Obstetricians and Gynecologists has recommended routine screening and brief interventions for substance use during pregnancy. Marijuana use is emerging as an area of particular concern for childbearing women—for whom marijuana is the most commonly reported illicit drug [1]—given the associated risks for both mothers and infants. For instance, cannabis users are at increased risk of depression, and children exposed to marijuana prenatally have impaired outcomes across several cognitive domains [2,3]. Among a national sample of adolescents aged 12-17 years, 6.5% reported current marijuana use, and 12.0% reported use in the past year [1]. When compared with nonpregnant adolescent girls, pregnant adolescent girls reported rates of marijuana use that were twice as high as nonpregnant peers (6.45% vs 14%, respectively) [4]. Studies have demonstrated that pregnant and nonpregnant women more commonly perceive regular marijuana use as having no risk to their health [5], which may be attributed to remaining areas of uncertainty in the literature regarding effects of marijuana use on the developing fetus, such as fetal growth [6,7]. This discrepancy between perceived safety and physician-identified risk is one of several obstacles that may exist for disclosure of stigmatized behaviors during pregnancy. Technology can help to overcome such barriers. Social media posts can provide insight into young women’s perceptions of substance use that complements data from traditional qualitative research, providing direct observations of their posted views. With the widespread availability of smartphones and internet access, social media has changed the landscape of information gathering and sharing with respect to substance use among adolescents [8,9]. This study aims to characterize the frequency and content of Facebook posts regarding substance use in the year before pregnancy and during pregnancy among young mothers.

Methods

Facebook posts were mined from 43 young pregnant women (age 16-24 years) who were recruited as a convenience sample and consented from 2 Midwest primary care clinics that serve a predominantly low-income community. The text-based Facebook posts authored by consented women were extracted using the Facebook application programming interface (API). Posts were extracted at study recruitment (typically in the first trimester) and again later in pregnancy (typically in the second or third trimester). At study recruitment, women also provided demographic information, estimated date of delivery, and the date they recalled discovering they were pregnant. During each data extraction, study participants logged on to their Facebook account to grant access, and access was lost once they signed out. Natural language processing was used to identify posts related to substance use by searching posts by keywords (eg, drunk, drugs, pot, and meth) and their morphological variants. Keywords included common synonyms and brand names for alcohol, tobacco, and illicit drugs and were supplemented by internet searching for colloquial synonyms and slang. Additional words were added from synonyms of derivationally related forms from a lexical database, WordNet [10]. Multimedia Appendix 1 provides a full list of keywords that were searched. These identified posts were separated by time stamp into prepregnancy and pregnancy posts. Facebook posts that occurred during pregnancy were identified by a timestamp occurring after the subject’s last menstrual period (LMP), which was imputed from the estimated date of delivery. Facebook posts that occurred within the year prior to pregnancy were identified by a timestamp occurring <1 year prior to the LMP. Substance-related post frequency was compared before and after subjects discovered they were pregnant, using the paired sample *t* test. Using mixed-methods techniques and an inductive framework, 2 investigators (DO and GTW) coded and identified major themes around substance use. Notably, only English-language posts were coded. Codes were derived iteratively, and a formal codebook was established after consensus or discussion between at least 2 investigators, with a third investigator (TC) resolving any disagreements. Posts were not required to identify self-use by the subject to be coded as substance-related. Outcome measures include the frequency of posts and major themes expressed regarding substance use before and during pregnancy. This study was approved by the Institutional Review Board of the University of Michigan (HUM00104989).

Results

Quantitative Results

This study included 43 young women aged 16-24 years. Table 1 presents participants’ characteristics. Facebook posts were last extracted at a median of 33 weeks gestational age. Approximately 2% of posts were in Spanish and not analyzed. Facebook posts revealed that young women are discussing the use of substances, predominantly marijuana, alcohol, and tobacco (cigarettes, hookah), before and during pregnancy (Table 2). Overall, 70% (30/43) of subjects posted about substances during the 1 year prior to pregnancy through the end of pregnancy. Furthermore, 56% (24/43) of subjects posted about substances during their pregnancies.

Table 1. Demographic characteristics of participants (N=43).

Demographics	Value
Race (n=43), n (%)	
Non-Hispanic black	21 (49)
Non-Hispanic white	11 (26)
Hispanic	7 (16)
Non-Hispanic mixed race or other	3 (7)
Native American	1 (2)
Age in years, mean (SD); range	21 (2.3); 16-24
Age group in years (n=43), n (%)	
<18	4 (9)
Between 18 and 21	19 (44)
>21	20 (47)
Educational status (n=43), n (%)	
Completed some high school	13 (30)
High school graduate	20 (47)
Completed some postsecondary education[a]	10 (23)
Median household annual income in US $ (n=28)[b], median (range)	3800 (0-40,000)
Household members (n=42)[c], n (%)	
Subject's children	12 (29)
Parent	11 (26)
Significant other (boyfriend, fiancé, husband)	11 (26)
Roommate	5 (12)
Lives alone	2 (5)
Relationship status (n=37)[b], n (%)	
Single, never married	16 (43)
In a relationship but not married	20 (54)
Married	1 (2)

[a] Subjects younger than 18 years were all counted as completing some high school; 2 of 4 were currently enrolled in school.

[b] Question not asked to participants aged <18 years.

[c] Categories not mutually exclusive.

Table 2. The number of substance-related and total Facebook posts.

Substance	Year prior to pregnancy	Pregnancy	Total
Marijuana	82	30	112
Alcohol	78	44	122
Tobacco	11	8	19
Other[a]	6	13	19
Total substance references[b]	177	95	272
Total Facebook posts	9816	13,043	22,859

[a] Heroin, prescription drugs, cocaine, lysergic acid diethylamide, ecstasy, unspecified recreational substances.

[b] Posts sometimes referenced >1 type of substance use.

Figure 1. Facebook post frequency in the year before pregnancy and during pregnancy. aPregnancy month is the number of 4-week intervals before or after the last menstrual period. Dashed line, the average time in pregnancy at which subjects reported discovering their pregnancies (each subject reported the date when she discovered she was pregnant during the study intake process; mean 2.2 pregnancy months).

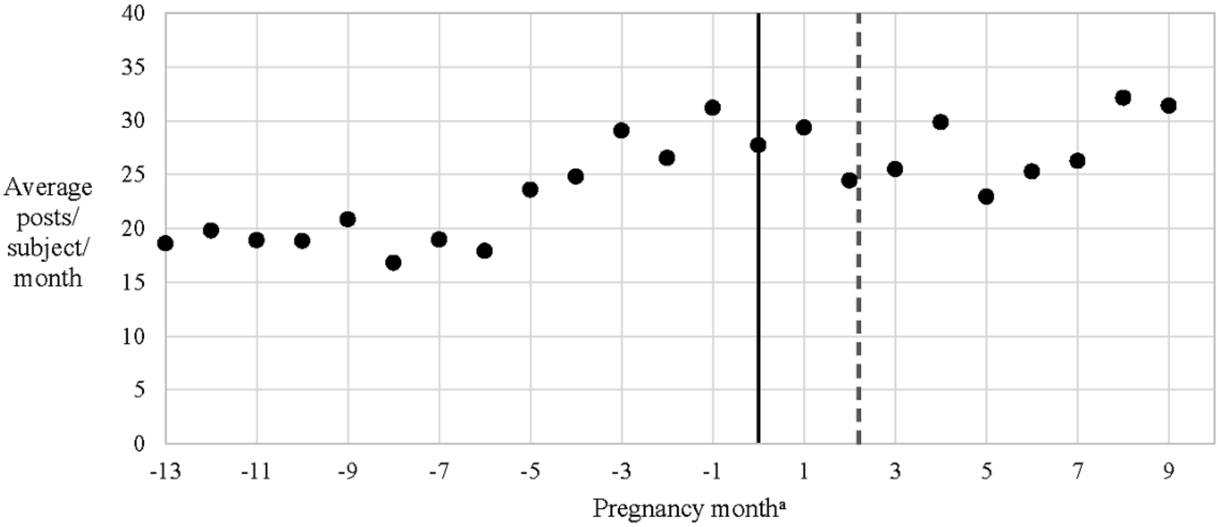
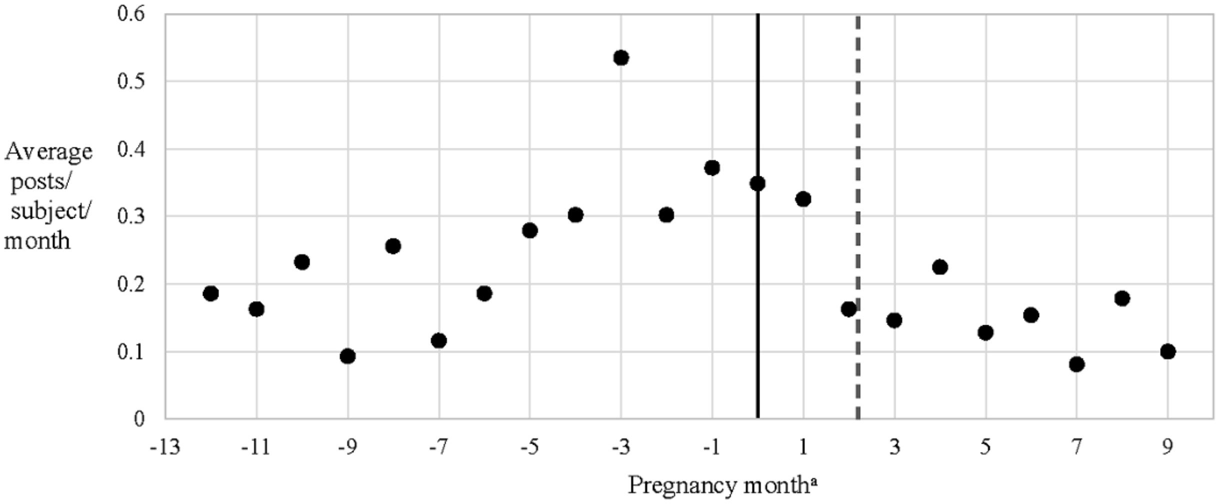


Figure 2. Substance-related Facebook post frequency in the year before pregnancy and during pregnancy. aPregnancy month is the number of 4-week intervals before or after the last menstrual period. Dashed line, the average time in pregnancy at which subjects reported discovering their pregnancies (each subject reported the date when she discovered she was pregnant during the study intake process; mean 2.2 pregnancy months).



The average total Facebook posting frequency (not restricted to posts about substance use) did not appear to change appreciably throughout pregnancy. However, the number of posts about substance use appeared to decrease after pregnancy compared with before pregnancy, most markedly after the date on which participants found out that they were pregnant (Figures 1 and 2). The paired sample *t* test supported a mean difference in substance-related post frequency between the periods before and after subjects discovered their pregnancies (t_{42}=2.3, *P*=.03).

Qualitative Results

Posts that reference substance use in the year prior to pregnancy (Table 3) predominantly focused on use or anticipated use of substances by subjects (118/158, 75% of substance-related posts; “i'm bout 3 shots from drunk tf”). Posts were unlikely to contain an overt value judgment about substance use, but generally referred to substance use in a positive or neutral tone (“I do love my vodka lol”). The most common themes of posts were cravings for substance use (“man i'm up, need to find weed and smoke asap. i fucking hate credit cards bruh”) and references about intoxication (eg, high, drunk, etc; “ima lil tipsy bih right now [4 smiling face with horns emojis]”). Posts describing social substance use (such as use with a friend or at a party) again typically described self-use by subjects (29/32 posts) but often suggested comradery-building (“someone come threw and smoke…i mean shit, we'll become friends! lmao!”).

Table 3. Post categories and representative posts in the year before pregnancy. Emojis are denoted by brackets. Beginning of pregnancy defined as the last menstrual period as estimated by the due date. "In a relationship" designates subjects who self-describe as "In a relationship, not married."

Post categories and subjects	Weeks before pregnancy	Posts
Cravings for substance use (n=30, average 20 weeks prior to LMP[a])		
Non-Hispanic mixed-race 22-year-old high school graduate, in a relationship	8 weeks	"I swear a blunt would be so legit [face with tears of joy] [face with rolling eyes]"
Black 19-year-old high school graduate, in a relationship	9 weeks	"I need some weed."
Black 22-year-old, completed some college, single	10 weeks	"i just want to smoke a fat ass blunt eat some subway and watch movies all day. put in apps on my phone"
Black 24-year-old high school graduate, relationship status unknown	37 weeks	"I need a drink like right now"
Black 24-year-old high school graduate, in a relationship	47 weeks	"I feel like drinking a whole bottle of liquor right now [tropical drink]"
Intoxication (n=32, average 20 weeks prior to LMP)		
Black 22-year-old, completed some college, single	15 weeks	"last night I was drunk! af #lilcuzbigcuz [woman's name]"
Non-Hispanic mixed-race 22-year-old high school graduate, in a relationship	18 weeks	"I'm so high I ain't never coming down..."
Black 24-year-old high school graduate, relationship status unknown	24 weeks	"drunk moments with [woman's name] [face with stuck out tongue and winking eye] [face with stuck out-tongue and tightly closed eyes] [face with tears of joy] [cocktail glass] [tropical drink] [wine glass] [beer mug] [clinking beer mugs]"
Non-Hispanic mixed-race 19-year-old high school graduate, in a relationship	30 weeks	"I wish I could just drink the pain away but that never works I tend to think about everything when I'm drunk and cry about it"
Black 16-year-old, enrolled in high school, relationship status unknown	52 weeks	"i'm high ass hell && hungry ass hell im ready to go home"
Social substance use (n=32, average 16 weeks prior to LMP)		
Non-Hispanic mixed-race 22-year-old high school graduate, in a relationship	8 weeks	"sipping on this gen and oj with mines [red heart] [smiling face with heart-shaped eyes] [couple with heart] [smiling cat face with heart-shaped eyes] think i'm a lil tipsy, [man's name] baby sitting his drink [person's name] what about you and bro? lol"
Native American 21-year-old, completed some college, single	10 weeks	"off three hours of sleep and a half pint of henny! but its money to be made, thanks to [man's name] for turning up at 1am.. i'm so slow motion"
Black 24-year-old high school graduate, in a relationship	18 weeks	"were my real bitches at like fr i wanna turn up shit if you come over we can have drinks smoke and i'll feed you lol"
Black 19-year-old high school graduate, in a relationship	14 weeks	"a friendship go two ways just like a relationship if you ain't putting no effort to talk, hang, get high lol whatever the case may be then neither am i fuck it [open hands sign] [100 points symbol]"
Black 23-year-old, completed some vocational training, single	52 weeks	"i love my cousins...we drunk as fuck!!"
Nonsocial substance use (n=17, average 25 weeks prior to LMP)		
Hispanic mixed-race 20-year-old, completed some high school, in a relationship	8 weeks	"gonna drink this hen dog and watch elf"
Black 22-year-old, completed some college, single	10 weeks	"why am I drunk by myself? lol"
Black 19-year-old high school graduate, in a relationship	12 weeks	"just getting off. about to run some bath water, roll up a blunt, & chill [smirking face]"
Black 24-year-old high school graduate, in a relationship	29 weeks	"it feels amazing to walk into your own home roll a blunt and relax [smiling face with smiling eyes] i hate paying bills but it is worth it"
Black 20-year-old high school graduate, single	35 weeks	"about to take my daughter to the park then make pepper steak for dinner theeennn sip my wine n a candle lit bubble bath [two women holding hands] [fork and knife] [curry and rice] [wine glass] [bath] [unidentified emoji]"

[a] LMP: last menstrual period.

Table 4. Post categories and representative posts during pregnancy.

Post categories and subjects	Gestational age[a]	Did subject know she was pregnant?	Posts
Negative aspects of or abstinence from substance use (n=30, average gestational age 16 weeks)			
Black 22-year-old, completed some college, single	6 weeks	No	"I can't turn up y'all! 4 days no drinking 4 days no squares and 3 days no weed! If you not helpin keep it pushing please and thanks"
Black 19-year-old high school graduate, in a relationship[b]	14 weeks	No	"y'all don't understand how i miss being turnt up [weary face][c] [broken heart] i love my love bug waaaayyyy too much tho! but valentine's day?? it's going tf dowwwnnnn i know my boyfriend gone get me drunk asfffff [weary face] [smiling face with heart-shaped eyes] [smiling face] [face with tears of joy] [face with tears of joy]"
Non-Hispanic white 18-year-old, completed some college, in a relationship	14 weeks	Yes	"what the fuck????? legalizing heroin? why the hell would anyone legalize heroin. i guess another thing to help population control fucking government."
Non-Hispanic white 20-year-old high school graduate, in a relationship	16 weeks	Yes	"if you smoke in a car with a pregnant person as your passenger, windows rolled down or not, you're an asshole."
Black 23-year-old, completed some postsecondary vocational training, in a relationship	31 weeks	Yes	"idk what type of rats yall niggas used 2 but i clearly was raised differently & im not changing who i am 4 nobody. i dont like all types of people in & out my house. especially niggas. i have a daughter. she will never think that shit is ok. if you cant respect that; im not the one 4 you. all that drinking & shit every day/night will not be done in my house. i wasnt raised seeing that shit & my kids wont be neither. yes i smoke weed; if i didnt a lot of mfs wouldnt be breathing so if you dont agree; fck you."
Social substance use (n=16, average gestational age 14 weeks)			
Black 24-year-old, completed some college, in a relationship	3 weeks	No	"seriously tho. we cant hang if i'm the only one high. it doesn't work like that no more unless we're close and you have a good reason for not smoking. lol"
Non-Hispanic white 22-year-old high school graduate, married	11 weeks	Yes	".. wish i had friends to talk to but i guess that now that i cant drink no one wants to hmu anymore anyways... its kool yall weren't real friends anyway.."
Non-Hispanic white 19-year-old, completed some high school, in a relationship	26 weeks	Yes	"is anyone interested in coming to a diaper party anywhere from now to 8? bring a pack of diapers and get all you can drink keg and food!!!! in jeremy wayne lambert"
Black 21-year-old, high school graduate, single	29 weeks	Yes	"lmbo [woman's name] said im blessed because i told her when [man's name] take me out to eat im allowed to get a drink and dessert lmbo"
Intoxication (n=15, average gestational age 22 weeks)			
Non-Hispanic white 17-year-old, not enrolled in school, relationship status unknown	6 weeks	Yes	"if you've ever seen me drunk, press like. if i get more than 30, i clearly need help...[face with tears of joy] [clinking beer mugs] haha.."
Black 23-year-old, completed some vocational training, in a relationship	18 weeks	Yes	"its sad scrolling down my tl & seeing mothers fcked up every weekend. weekdays too smh. your child is going 2 remember you as a drunk. (if they remember you at all b/c you're always putting them on the next while you turn up) but watch these same bitches dog their baby daddies tomorrow on fathers day! smh."
Non-Hispanic white 18-year-old, completed some college, in a relationship	32 weeks	Yes	"happy 21st birthday to my love [man's name]. i hope you have a wonderful birthday and dont end up with alcohol poisoning from drinking so much. i love you and i wish you have the best day possible. have a good day![4 face throwing a kiss] [4 party popper]"
Black 24-year-old, completed some college, in a relationship	34 weeks	Yes	"get high all you want baby girl.!! smoking does kill but we ain't talking about weed.!!"

Post categories and subjects	Gestational age[a]	Did subject know she was pregnant?	Posts
Cravings for substance use (n=7, average gestational age 11 weeks)			
Black 22-year-old, completed some college, single	6 weeks	No	"who in the green with some weed?"
Non-Hispanic mixed-race 19-year-old high school graduate, in a relationship	6 weeks	No	"i could go for a shot and a j and a bus bit hey you don't see me doing that so don't tell me shit about #!++!#? a &!@$ that is my!%+@#$"
Black 23-year-old, completed some vocational training, single	20 weeks	Yes	"i wish i could drink, i'm so irritated!"
Black 19-year-old high school graduate, in a relationship	21 weeks	Yes	"if i could just smoke a wood.. i wouldnt give a fuck about shit."

[a] Gestational age reported as weeks after the last menstrual period as estimated by the due date.

[b] “In a relationship” designates subjects who self-describe as “In a relationship, not married.”

[c] Emojis denoted by brackets ([ ]).

Fewer substance-related posts during pregnancy (Table 4) described substance use by subjects (28/76, 37%) than in the year prior to pregnancy (118/158, 75%). Of posts describing self-use during pregnancy, the majority was written before subjects discovered they were pregnant (18/28, 64%). The most common theme was discussion of negative aspects of substance use (posts discussing abstinence from substance use were also included in this theme). These posts described the dangers of substance use among pregnant women and their concerns about use around their family or themselves during pregnancy (“i hate it when people who smoke cigarettes come all up in my face and talk to me. if you don't get yo nicotine tobacco smelling ass breath out my face...... ugh.”). Some of these posts demonstrated ambivalence about the types of substance use (“smoking does kill but we ain't talking about weed”) or complete abstinence (“4 days no drinking 4 days no squares and 3 days no weed!”). Another common theme was a discussion of social aspects of substance use. These posts often referred to the social challenges of abstinence (ie, lack of social interaction that includes substance use; “where are the people that know how 2 communicate? can have good conversation w/a sense of humor w/o being drunk or high? too many negative nancy's around here, positive vibes only!”). Furthermore, major themes included craving substances (less common than in the year prior to pregnancy) and references to intoxication (most commonly referring to intoxication in others).

Discussion

Principal Findings

We characterized Facebook posts regarding substance use in the year before pregnancy and during pregnancy among a sample of young mothers. We found that the frequency of posts related to substances decreased after subjects discovered they were pregnant; this may represent a decline in the presence of substance use among the lives of young women when they become pregnant or may represent a social stigma of discussing substance use while pregnant. We are not aware of prior research that captures the total or substance-related social media posting frequency throughout pregnancy, though a cross-sectional study showed pregnant women frequently check social media [11].

Pregnancy is a window of opportunity that prompts the majority of women to either reduce or abstain from alcohol and substance use for the remainder of their pregnancy [12]. Many of the substance-related Facebook posts we identified during pregnancy reflected this increased focus on abstinence from and negative consequences of substance use. However, a subset of women continue using substances during pregnancy [1,4]. Our sample of pregnant young women often discussed substance use in ways that highlighted the need for continued interventions to support their abstinence from substances during pregnancy. For instance, women in our sample often expressed a loss of social support because they were not able to participate in the social use of substances; this is similar to a prior qualitative study of Australian women who identified social alcohol consumption as motivation for continued use throughout pregnancy [13]. Unique to this study, some of the posts suggested social abandonment instead of simple loss of social activities: “bitches don't hit you up to check on you if you ain't got a bottle or a blunt.” This finding may reflect a study population with fewer baseline social resources and is amplified by the vivid verbiage found in Facebook posts throughout our sample. Furthermore, although the women in our sample appeared to have knowledge about the need to abstain from substance use during pregnancy, they often expressed some ambivalence about the need to avoid all substances at all times, particularly marijuana. Reportedly, marijuana use during pregnancy is on the rise [14], increasing by 62% over the past decade; this increase has been attributed, in part, to an increased perception of the safety of marijuana use during pregnancy [4,5]. Clinicians should acknowledge the role of substance use in the lives of youth and find ways to ensure these young women are supported and empowered to make healthy decisions during pregnancy.

Disclosure of sensitive topics, such as substance use during pregnancy, is challenging because of social stigma, but can be facilitated by the use of technology. Social media posts by young women can provide valuable insight into their perceptions of substance use during the vulnerable time of pregnancy, with observations unencumbered by a formal research setting. Such information can be used toward preventive efforts in reducing use during pregnancy by identifying the circumstances around why substances are used (ie, social support and addiction) and assist in targeting resources and programs for at-risk mothers.

Limitations

Although this study represents a novel investigation of substance use, it has a number of limitations. Despite an extensive database of search terms, it is possible that some posts were missed owing to posts with nonsemantic use of words that refer to risk-taking behaviors or novel slang not found during internet searching. However, search terms were identified using a variety of methods that included modern youth-centered vernacular. In addition, some posts related to substance use may be posted through pictures only, which were not analyzed in this study. Posts were extracted at 2 times in pregnancy (at enrollment and a later date in the second or third trimester), and anticipated extraction of posts could have introduced a potential desirability bias; this is felt to be less likely as the research team is only a small part of a much larger audience that would be anticipated to read the posts. Moreover, the quantitative analysis of post frequency is limited by the small sample size and a relatively low proportion of substance-related posts. However, the qualitative data collected provides important nuance and context to these dangerous behaviors among a high proportion of young mothers in our diverse sample. Finally, although our sample included a diverse range of race or ethnicities, findings from our small study may not be generalizable to larger populations of youth.

Conclusions

Our evaluation of Facebook posts reveals that young pregnant women are discussing the use of substances, predominantly alcohol and marijuana. Providers that care for young pregnant mothers can anticipate and acknowledge the possible loss of social interaction related to substance use and support women in remaining abstinent throughout pregnancy. Future work that explores youth-centered interventions to prevent and treat substance use before and during pregnancy among young, at-risk mothers could improve outcomes for both mothers and their children.

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Authors' Contributions

TC, VGVV, XZ, and LPN contributed to the design and data collection. TC, DO, and GTW contributed to the analysis, interpretation, and writing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search terms used to query database of Facebook posts.
[PDF File (Adobe PDF File), 54KB - pediatrics_v1i2e10261_app1.pdf]

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Abbreviations

LMP: last menstrual period

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