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The Evolving Family Mealtime: Findings From Focus Group Interviews With Hispanic Mothers

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Abstract

Background: Given the protective effects of shared family mealtimes and the importance of family in the Hispanic culture, this context should be explored further to determine how it can be leveraged and optimized for interventions.

Objective: This study aimed to explore contextual factors associated with family mealtimes in Mexican and Puerto Rican families.

Methods: A total of 63 mothers participated in 13 focus group interviews across 4 states. Thematic analysis was used to analyze transcripts.

Results: Seven overarching themes were identified through the thematic analysis. Themes reflected who was present at the mealtime, what occurs during mealtime, the presence of television, the influence of technology during mealtime, and how mealtimes have changed since the mothers were children.

Conclusions: Hispanic mothers may be adapting family mealtimes to fit their current situations and needs, keeping the television and other devices on during mealtimes, and making additional meals for multiple family members to appease everyone’s tastes. All of these are areas that can be incorporated into existing culturally tailored obesity prevention programs to help families lead healthier lives.

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KEYWORDS

family mealtimes; healthy eating; technology at the table; parenting and mealtimes; Hispanic culture; obesity prevention

Introduction

The frequency of shared family meals is associated with healthy eating practices in children and adolescents [1]. Family meals provide an opportunity for family members to connect, and consume healthier food (ie, fewer calories and less fat) than food consumed outside of the home [2,3]. Some studies have also shown a connection between family meals and weight, with the frequency of family meals linked to a reduced risk of being overweight in early adolescent females [4].

Hispanic children have a higher rate of obesity (25.8%) than other ethnic groups [5] and the family mealtime is an important context for promoting healthy eating habits. One study found that 78.3% of Hispanic immigrant families regularly eat a family meal together (ie, every day), and this percentage was even higher when they lived in their home country [6]. Research has revealed that the frequency of shared family meals is associated with increased fiber, fruit, and vegetable consumption in Hispanic youth [7]. Although Hispanic mothers place a high value on family mealtimes, they acknowledge that it is not always possible to regularly eat together as a family [8,9], noting that lack of time and busy schedules present challenges. In addition to shared mealtime frequency, watching television during mealtimes is linked to poorer dietary quality in 10-14-year-old Hispanic children [10]. Given the high value placed on the importance of family in the Hispanic culture, and the protective effects of shared family mealtimes, this context should be explored further to determine how it could be leveraged and optimized for interventions. Thus, the purpose of this study was to explore mealtime frequency and contextual factors associated with family mealtimes in Mexican and Puerto Rican families.

Methods

Sample Selection

To participate in the study, participants had to be of Mexican and Puerto Rican descent, and to have a child between 6 and 18 years of age. Participants were recruited via flyers and referrals from community organizations that serve Hispanic families. Flyers were posted and distributed at churches, grocery stores, flea markets, community centers, laundromats, clinics, and recreation centers. Interested families were asked to contact project research staff. A total of 63 mothers participated across 13 focus groups between June 2015 and August 2018. On average, 5 mothers participated in each focus group session, which on average lasted 1 hour in duration. Trained bilingual facilitators conducted the interviews in Spanish at locations that were convenient and comfortable for mothers and ensured privacy (eg, private conference rooms in community clinics, community centers, county extension offices, and university campuses). An interview guide that included the focus group questions and follow-up probes was used for each interview. Previous studies, as well as a review of the literature, informed the development of the guide. The interview questions are included in Textbox 1. Small focus group sessions were selected as the methodology, as the goal was to have open and in-depth discussions with mothers about their family mealtime practices and beliefs.

Ethics and Consent

This study was approved by the Institutional Review Boards at California State University, Fresno, Iowa State University, University of Houston, and the University of Illinois, Urbana-Champaign. Written informed consent was obtained from all participants prior to conducting the interviews.

Textbox 1. Interview questions.

Carrying out mealtimes: Mealtimes happen in many different ways for families.

- Who does the cooking and grocery shopping in your home?
- How often?
- Do your children ever help with either?
- Are your family meals different than when you were a child?

Some families are casual or spontaneous about cooking and shopping. They see what is available and go from here. Others make a plan and use it to shop and cook. And some are in between.

- What is your family like?
- What determines what you serve for meals?
- Do you choose things on sale; use leftovers; have a weekly menu planned ahead?
- What does a “family meal” look like in your house?
- Who is typically there? Describe what all happens during family meals (music, television, conversation, homework, etc)
- How often do you have a “family meal?”
- Are your family meals “traditional”? If so, how or if not, why not?

Data Collection and Participants

This study is part of a larger multistate randomized controlled trial, *Abriendo Caminos*, an obesity intervention program culturally tailored for Hispanic families [11,12]. The intervention is a 6-week program that focuses on nutrition, family mealtimes, and family physical activity, and is described in detail elsewhere (see [11,12]). Results from this study were used to help guide the content and implementation of the intervention by learning about the needs of the communities in which the intervention would take place. This study was conducted across four states (California, Illinois, Iowa, and Texas) that were selected due to large concentrations of Hispanic families across the state or within rural communities in the state. Focus group interviews, a methodology that is well suited for exploratory research [13,14], were used to explore practices and beliefs regarding family mealtimes among Mexican and Puerto Rican families in each state.

At the beginning of each focus group interview mothers completed a demographic questionnaire that included questions regarding their date and place of birth, generation status, language preference (both spoken and written), educational attainment, religion, marital status, number of children, employment, annual household income, and the number of people the income supports. In addition, a question regarding how mothers rated their general health was included. Mothers were offered an honorarium (ie, US $10 gift card or cash) for their participation in a focus group session.

Data Analysis

All focus group interviews were audio recorded and transcribed verbatim in Spanish. Then, 2 Spanish proficient, bilingual research assistants independently back-translated the focus groups to English. Next, these back-translated interviews were double-checked for accuracy and phrasing by multiple team members. Dedoose version 8.3.35 [15], a qualitative software analysis program, was used to code transcripts. Thematic analysis, a systematic and iterative approach to help patterns in the data to be discovered and identified, guided the analytical process [16].

Two researchers (AJH and Stephanie Sloane) fully familiarized themselves with the transcripts by reading through them numerous times, and then initially identified codes independently for comparison purposes. Initial code creation was based on ideas that were identified from reading the transcripts as well as preliminary patterns of similarity. Researchers then refined the codes and applied them to the transcripts. As researchers coded the narratives, they continued to compare the codes throughout the process to broaden the comprehensiveness of the codes and ensure consistency in the coding process. In the next step, codes were categorized into initial themes based on the repeated patterns that had been identified in the data. The narratives were then read again to refine the themes. In the final step, quotes were selected that fit these themes [17]. Researchers discussed the appropriateness of the quotes, and a consensus was reached when disagreement was present. Preliminary findings were shared with a note-taker of the focus groups to establish credibility of the findings further and for researchers to enhance the themes.

Results

Demographics of Study Mothers

Mothers' ages ranged between 17 and 74 years (mean 39.8 [SD 10.23]). Most mothers were married (38/63, 60%) and on average had 3 children (mean 3.13 [SD 1.90]). The mean number of years of formal education the mothers achieved in the United States was 4.7 (SD 5.67), compared with 7.96 years (SD 3.54) in their country of origin. More than half (37/63, 60%) of the mothers reported that their families' annual household income was US $29,999 or less, which is considered a low income for a family of 4 in the United States. The vast majority of mothers (50/63, 79%) were born in Mexico. A small percentage of mothers were born in the United States (8/63, 13%) or other countries not disclosed by mothers (5/63, 8%). Nearly half of the mothers reported that they spoke only Spanish (28/63, 44%) or spoke Spanish better than English (25/63, 40%), and that they read only Spanish (26/63, 41%) or read Spanish better than English (21/63, 33%). On average, the mothers had lived in the United States for 18.5 (SD 7.46) years.

Seven overarching themes, as well as salient quotes to illustrate themes, were identified through thematic analysis. Themes reflected who was present at the mealtime, what occurs during mealtime, the presence of television, the influence of technology during mealtime, and how mealtimes have changed since the mothers were children. Findings are presented across the 4 sites because no consistent regional differences emerged.

Theme 1: Mothers and Children Are Usually Present at Mealtime

The majority of mothers talked about how their husbands were usually working late, so they (mothers and children) would eat without them.

> *Yes, only my husband is not present. As long as he brings in the money for food, there is not a problem.*
>
> *Me too, like normal, never, well, it is very rare that I eat with my husband who comes home around 9 or 10pm "..." only with the children.*
>
> *My husband eats when he gets a chance. We eat at different times.*

Some mothers expanded on this and gave additional explanations for why they would eat separately, including that the children could not wait until father gets home because they were too hungry, and that making them wait would be unfair to them. Therefore, family mealtimes had to occur at different times, and as a result would not include the whole family. For example,

> *Same, during weekdays is only the baby and me. Same, I make her food, and I eat with her. Moreover, during the afternoon it is normally the four of us because the three girls and my husband gets home very late, he has to eat by himself. My daughters come out of school and get home hungry; it is not fair for them to wait for their father. We do not wait for him because he comes home one hour later. During the weekend, we do have breakfast all together.*

A minority of mothers stated they would eat first with their children, and then sit again to eat with their husbands when they got home. In some cases the entire family (with the children), or just themselves and their partner, would be at the table.

> *My husband does not come home until 6, and sometimes we have already eaten, but when he is at the table, we all sit with him to a eat a fruit or whatever and we accompany him. For me, 6 is too late to eat but my husband does not like to eat alone.*

Other mothers said that they also did not want to eat late, because it would be bad for their health, lead to weight gain, indigestion, and/or difficulty sleeping, so they would eat earlier with the children.

Theme 2: Fathers Are More Likely to Be Present at a Family Meal During the Weekends

Mothers also talked about how fathers would be more likely to share a family meal on the weekends because they usually did not work on the weekends. Fathers' work schedules, as well as busy schedules, in general, could preclude family meals (where every family member was present) from occurring during the weekdays, but weekends freed up more time.

> *Almost all family meals are on weekends.*
>
> *Only on the weekends when we are together, the three of us we eat the three together.*
>
> *But for job reasons or work schedules, we do not eat together until Saturday and Sunday. Those days we can sit together. However, weekdays it is difficult due to everyone's schedule.*

Some mothers shared that the family meal would be a big breakfast, whereas others said it would be lunch or dinner, with some saying all 3 would be meals that would be eaten as a family and specifically reserved for this purpose on the weekends.

Theme 3: Mealtimes Are for Talking and Checking-in With One Another

Mothers discussed how they liked to spend time during the meals talking and catching up with family members. Some talked about how this is a special time and an opportunity to check-in. They valued this time and viewed it as an opportunity to see how each other's day went and to see how everyone was doing. Other mothers talked about how it is a way to connect and joke with one another, as one mom shared, "there is chatting going, we tell jokes, and we talk". Some said the conversations would continue long after the meal ended because family members enjoyed each other's company and the opportunity to be together.

> *We talk about how things went at school, how things went at work, because two of my older sons go to school and work too. So, we would talk about what we are doing. I would talk about my work because that is where I let out my stress.*

Not all of the family members enjoyed the conversation time in the same way, however, as some mothers talked about how children were eager to get back to television, their phones, or tablets.

> *At the table we sometimes spend two hours talking and we are not eating anymore; we are just talking. Sometimes my son gets mad because we spend too much time at the table talking. I say, "What is the matter", he says "I want to use my iPad". He is young, but sometimes he acts like a big boy, right?*

A few mothers talked specifically about rules that they have forbidding devices being at the table, or the television being on, because they want to use this as a time for connection through conversation.

> *Well since December I have been living alone with my kids. So, right now it is myself and my 3 children at the table. No television or tablets. We use the table time to talk and ask questions like how it went at school, and my children ask me how it went at work. That way, we use the table time for my children to share with me what they think, and what they want.*
>
> *We usually always eat the three of us together and we do not have the television on. We stopped watching television while eating when I divorced my ex-husband because he did have that habit. But we always try to enjoy the moment and also talk or make plans about what we are going to do in the afternoon, where we are going to go, where we are going to walk, we go to the cinema. I feel that this moment is ours, this moment of eating.*

Theme 4: Television Is Largely a Part of Family Mealtimes

Mothers talked about whether or not the television would be on during the meal. The majority of mothers said the television would be on during the mealtime. For some families, having the television on during mealtime was the norm, but it would sometimes have to be turned off mid-meal because children would be paying more attention to the television than eating. One mother shared,

> *I do watch the TV. I turn it off if they were not eating (and watching the TV instead). They are only paying attention to the TV and I like to talk to them, ask them what they did and then they talk to me about their adventures.*

Some mothers also talked about how family members can be talking and watching television at the same time, "Yes, we have the TV on and sometimes if we do watch TV, we are still talking", and that that was the norm in their family. One mom stated that "There are times that the TV is on, simply because we are used to talking, we are used to the noise." A few said that they did not talk during meals, they served their food and then watched television as a family, and that this was preferred over talking with one another.

> *Sometimes I call them so we can eat together but no, it is better to take the food to the living room to eat it in front of the TV.*
>
> *Each one of us serves our own food and then we go and eat in front of the TV.*
>
> *In my house, I do not watch TV, but my daughter likes to. If the TV is on, she is not eating well because she likes the movie that is running, she pays attention to it.*

Family rules regarding television being on or off was also part of the discussion. Some discussed how they wanted to continue the rules that they had when they were children, while others said the opposite. Some mothers shared how their husbands wanted the television to be on as they looked forward to watching television after a long day after work, and that mothers wanted to respect that, so it would be on during the meal.

> *In our house, the television is close by. It is actually set in front of us. OK, when my husband arrives, he wants to sit down to eat and watch the television.*

While overall, many of the mothers said television would be on during the meal, a few said they would make sure it was off because it was distracting to the children and would prevent them from eating their food. A comment from one mother highlights this, *No, no I do not have TV or anything like that in the dining room. Because I want the children to focus on the food. And it is healthier. So that is the way we manage, we try to focus on talking amongst ourselves. It's a bit difficult for the children.*

Theme 5: Influence of Technology on the Family Mealtime

The influence of technology during mealtimes appeared to be mixed. Some of the mothers voiced frustration about devices at the table, saying they would tell the children that they need to eat and to put the devices away. Although some mothers expressed that they did not want technology to be used while eating at mealtime, many of them said that their children insisted on having devices with them during this time, and that it had become a regular source of argument.

> *Hardly anyone is eating, because they will tell me it is not yummy. And I will tell them to leave cell phones, to put them away so they can focus on their food. And my children tell me "Mama, look at what is happening," and I will tell them they need to focus on eating!*

Some said they felt using technology at the table was disrespectful and that children needed to learn the rules. Others talked about rules they had against having devices present at the table "No television or tablets" and negative emotions around them.

> *Well, they are married and have their own house, but it makes me angry when we sit down to eat, and they are on their phones.*
>
> *Well, I punished my son so he can understand me. I told him, "Well, okay, use the cell at the table, but I am going to punish you". And he did not use it. And he went and left it in his room or where I will not see it.*
>
> *I try to make sure my daughter does not have her phone or iPod close. She has to do all of her homework and clean her room to have it. It is like a reward.*

Still, other mothers said that devices were present during mealtimes and that this was just part of what happens during the mealtime.

> *Sometimes, there are phones present, or they will go and watch TV.*
>
> *We will sometimes eat together and at other times, we will eat separately with our cellphones at our sides.*

Theme 6: Mothers' Approaches to Meeting Multiple Food Preferences

Mothers talked about how they sometimes make multiple meals, one for their children, and sometimes even another separate meal for their husbands, creating a *buffet-style* mealtime. This often results in extra time being spent on meal preparation. Some mothers shared that they will try to get ahead of this problem by only making meals that they know everyone will enjoy, but that this limits the variety in their own diets, as well as in their children's diets.

> *That is why I say my house is like a buffet because I ask everyone what they want to eat and then make it. In my house, you will always see different types of food because we all do not eat the same thing; everyone always is eating something different due to their varied tastes. I can eat everything and anything but everyone else does not like eating what others eat.*
>
> *Sometimes I try for everyone to eat the same thing but normally that does not happen.*

Others said they refuse to make multiple meals and children have to eat what is being served, or not eat at all. They commented that they simply do not have the time to cater to each child's meal preferences.

> *And now that they spend time with me, they do not eat what I make, because I am not about to make another sort of food. It is double my work ...*
>
> *That is my husband. He says, "We do not have a buffet, eat what we have or do not eat."*

Nevertheless, many of the mothers said that their children's preferences are often taken into account when grocery shopping, as a way to ensure that the mealtime will go smoothly.

> *Yes, I almost always cook something they like to eat because I know they like it. So that way I know what I cooked they will be willing to eat.*
>
> *In my house, when we go grocery shopping, we always think about what the children will like. If necessary, we will have to make two meals, one for the big ones (adults) and one for the boys, the children.*

Theme 7: Family Meals Are Different From When Mothers Were Kids

Mothers discussed how their mealtimes today are different from what they were like when they were children. Some shared how they would have family meals with everyone present, but today it is harder to do that due to busy schedules, and that when the family sits down together it does not feel *complete.*

> *Okay, when I was little, the family would have family meals together. Now, we do not eat together as a family because the kids are in school, one goes to work and eats on a different schedule. It is rare when the entire family sits together for a meal.*
>
> *Well, yes. Here, it is rare when we eat together and back then we would all eat together.*

Technology also came up as a large contributor to making today's family meals different from when they were growing up. They expressed that technology today plays a role in reducing conversation, story time, and physical activity, and there was a sense that their children were missing out on these activities as a result.

> *I liked it when we were all together, because my husband and I are raising our daughters together but*

> *it is a different way of living because now there is the technology and we were raised without technology. We could play all day outside on the street with balls until our parents would holler at us to come home.*
>
> *When we were in Mexico, it was always the five of us eating together, always.*
>
> *Now each kid is in their own room or they are using their tablet or watching TV. We do not engage in the same activity as we did. Before, we... my dad and my mom were in the yard. They had us there, my dad would tell stories, everyone around, you know, a bunch of little eyes.*

Some mothers also discussed how the types of foods consumed today are different from what they ate when they were children, with a special emphasis on the freshness of the foods they consumed when they were growing up.

Discussion

Principal Findings

Knowing about the changing Hispanic family mealtime can help in developing interventions to promote healthy eating habits. According to mothers in the study, family meals, where everyone is present, were more likely to occur on weekends. The use of the television tends to be part of the family mealtime as reported by many mothers. Similarly, phones, tablets, and videos games are all elements of the current societal fabric and mothers take varying approaches to manage their use at the table. Mothers feel that family meals today are different from what they were like when they were growing up. Mothers reported that nowadays there were fewer family meals, where all family members were present. Mothers also indicated that the availability of technology influences meals in ways that did not exist when they were children. Immigrant families face time constraints, including longer working hours, which make juggling work roles and eating regular family meals more challenging [18-20]. Families in this study are still sitting down together to share a meal, just without all family members present. Families are adapting and finding different ways to eat together.

Some mothers discussed that family meals were profoundly meaningful and explicitly reserved for conversation and catching up with one another. While some mothers said that technology was not allowed at the table so as to minimize distractions, others talked about the television being a regular part of the mealtime, which is associated with a reduction in the benefits of sharing a family meal [21,22]. Watching television while eating is associated with a higher caloric intake [3,10] and poorer dietary health in children [22]. One study conducted in Brazil found that having the television on during the meal was associated with a higher intake of chips and parents spending more time encouraging their 6-10-year-old children to eat their food [23]. Another study found that the greater the insistence on eating, the higher the child snack consumption in 3-6-year-olds [24]. This study corroborates these findings as mothers talked about how their children would focus on the television rather than on eating, and they would get frustrated repeatedly asking them to focus on eating. A few mothers also talked about how fathers looked forward to watching television after a long day at work and so the television would be on during mealtimes with fathers. One focus group study found that Hispanic parents believe that turning the television off is an important way to help overweight children lose weight [25]. Getting both mother and father on board with turning the television off during mealtimes should be an important focus of future interventions. Including fun strategies for family time as a substitute for television may be an important component in family-based obesity programs.

In addition to television, other popular technology devices are commonly present at the mealtime and Hispanic mothers are trying to negotiate the use of them during their family mealtime. Some mothers believe strongly that devices should be absent from the table, others seem upset only if the children are distracted to the point of not eating. By contrast, others seem to accept that this is just part of what happens today. Mothers also talked about how their mealtimes when they were growing up were different and that technology presents unique problems today for connection and physical activity. Screen time is something that parents have to navigate today, and while technology carries benefits, finding a healthy balance is important to parents [26]. A mixed-methods study conducted with parents of preschoolers asked parents about their interest in technology use during mealtimes, with a focus on positive purposes such as educating children about healthy eating [27]. Parental interest in technology use during mealtimes was more negative than positive. Parents cited concerns around intrusiveness, reliance on screens, and distraction. While parents are largely uninterested in technology being present at mealtimes, their actual presence at the mealtime seems to be ubiquitous.

With research suggesting that use of technology during mealtimes might be associated with unhealthy eating, interventions should teach parents strategies to minimize the use of technology at the table. Using technology during meals is likely to make connecting with one another, especially through conversation, more challenging, and is also associated with less healthy eating (eg, [28]) and increased risk of overweight and obesity [29]. One family-based intervention, by Fulkerson and colleagues [30] aimed to reduce screen time during meals. Although the intervention was effective at improving child dietary intake, no significant effects were found on the reduction of screen time. However, another family-based intervention, Healthy Habits, Healthy Homes, was effective at reducing child television viewing in general, though the intervention did not target reducing television viewing in the mealtime context specifically [31]. More recently, a family intervention program that focuses on teaching low-income racially diverse parents and children meal preparation skills, Simple Suppers, has been successful at reducing television viewing during mealtimes [32]. Still, more research is needed in this area, especially regarding culturally tailored programs for Hispanic families.

Mothers in this study also reported meal preparation challenges. Because of having children and spouses with picky eating habits, mothers sometimes spent extra time making separate meals for individual family members. Preparing different meals for family members increased their workload and added extra burden to their limited resources. Mothers talked about how they would sometimes plan out meals in advance that they knew their kids would eat, and only purchase and make those foods as a way to minimize workload, conflict, and stress. One study found that making special meals for children with picky eating habits was related to less variety in children's diets as well as continued refusal to eat the original foods [33]. In a focus group study exploring opinions of intergenerational Hispanic family members, Hispanic youth discussed how parents' permissive parenting styles around food contributed to children's unhealthy eating habits [9]. They talked about how parents made it easy for them to develop unhealthy eating habits. Expecting children to eat the same food everyone else in the family is eating may be perceived positively by Hispanic youth when they are older. Sharing these findings with mothers may help empower them to make one meal for all family members, saving both time and energy.

Although fathers were invited to participate in the study, only mothers participated. Thus, the views here represent the experiences and perceptions of mothers only. Nevertheless, mothers are sitting down for mealtimes with their children regularly, even when fathers are not present, and they have an important influence on their children's dietary habits. Recent research has found that father absence from mealtimes is associated with greater child distractions in 18- to 24-month-old children [34]. Future research may want to examine how Hispanic father absence from weekday mealtimes may influence child behavior during weekend mealtimes. This study also focused only on Mexican, Mexican American, and Puerto Rican mothers. Future studies should examine other Hispanic subgroups to determine whether similar commonalities are found across different Hispanic subgroups. Lastly, there may be situations in which families incorporate certain behaviors, such as television viewing or screen time use, as a means to reduce conflict during mealtimes, relax or get things done, and change the mood [35]. There may be specific intentions behind some of these strategies, and the emotional and mental health of families concerning the use of screen time should be considered in conjunction with their physical health in interventions.

Conclusions

The Hispanic family meal is evolving, and researchers and practitioners can benefit from knowing what is happening during the meal and what challenges families are facing. The main take-away messages from this study are that Hispanic mothers may be (1) adapting family mealtimes to fit their current situations and needs (2) keeping the television and other devices on during mealtimes, and (3) making additional meals for multiple family members to appease everyone's tastes. All of these are areas that can be addressed in existing culturally tailored obesity prevention programs to help families create healthier eating habits.

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Authors' Contributions

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Conflicts of Interest

None declared.

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Original Paper

Trends in Web Searches About the Causes and Treatments of Autism Over the Past 15 Years: Exploratory Infodemiology Study

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Abstract

Background: Ninety percent of adults in the United States use the internet, and the majority of internet users report looking on the web for health information using search engines. The rising prevalence of autism spectrum disorder (ASD), uncertainty surrounding its etiology, and variety of intervention approaches contribute to questions about its causes and treatments. It is not known which terms people search most frequently about ASD and whether web search queries have changed over time. Infodemiology is an area of health informatics research using big data analytics to understand web search behavior.

Objective: The objectives were to (1) use infodemiological data to analyze trends in web-based searches about the causes and treatments of ASD over time and (2) inform clinicians and ASD organizations about web queries regarding ASD.

Methods: Google Trends was used to analyze web searches about the causes and treatments of ASD in the United States from 2004 to 2019. The search terms analyzed for queries about causes of ASD included vaccines, genetics, environmental factors, and microbiome and those for therapies included applied behavior analysis (ABA), gluten-free diet, chelation therapy, marijuana, probiotics, and stem cell therapy.

Results: Google Trends results are normalized on a scale ranging from 0 to 100 to represent the frequency and relative interest of search topics. For searches about ASD causes, vaccines had the greatest frequency compared to other terms, with an initial search peak observed in 2008 (scaled score of 81), reaching the highest frequency in 2015 (scaled score of 100), and a current upward trend. In comparison, searches about genetics, environmental factors, and microbiome occurred less frequently. For web searches about ASD therapies, ABA consistently had a high frequency of search interest since 2004, reaching a maximum scaled score of 100 in 2019. The analyses of chelation therapy and gluten-free diet showed trending interest in 2005 (scaled score of 68) and 2007 (scaled score of 100), respectively, followed by a steady decline since (scaled scores of only 10 and 16, respectively, in 2019). Searches related to ASD and marijuana showed a rise in 2009 (scaled score of 35), and they continue to trend upward. Searches about probiotics and stem cell therapy have been relatively low (scaled scores of 22 and 18, respectively), but are gradually gaining interest. Web search volumes for stem cell therapy in 2019 surpassed both gluten-free diet and chelation therapy as web-searched interventions for ASD.

Conclusions: Google Trends is an effective infodemiology tool to analyze large-scale web search trends about ASD. The results showed informative variation in search trends over 15 years. These data are useful to inform clinicians and organizations about web queries on topics related to ASD, identify knowledge gaps, and target web-based education and knowledge translation strategies.

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KEYWORDS

autism; infodemiology; infoveillance; informatics; Google Trends

Introduction

The world wide web is often the first source of information people use to find answers about health [1]. Ninety percent of adults in the United States access the internet today [2], and the majority of internet users report looking for health information on the web in the past year [3]. Nearly 80% of those searching the web for health information begin their query using search engines, such as Google, rather than a dedicated health website to find information [3]. While the media has given rise to widespread information about autism spectrum disorder (ASD), it has also given rise to misinformation about ASD that has contributed to or perpetuated misperceptions, myths, and trends related to the causes and treatments of ASD [4]. Understanding lay beliefs, misconceptions, and queries about ASD can help identify areas that require public education and improved awareness [5], and analyzing web search behavior is one way to do this. This information can help direct clinician-patient discussions and can be used by ASD and health organizations to help guide web-based content and the development of web-based education strategies and knowledge translation plans.

Infodemiology is a relatively new field of scientific research and methodology in health informatics that involves the study of the distribution and determinants of web-based information, and infoveillance involves surveillance by tracking and analyzing trends in these data over time [6,7]. Web-based search analysis tools, like Google Trends, can be used to analyze data from large populations in order to understand web search behavior surrounding specific topics.

Google Trends is a big data web tool that applies algorithms to assess the frequency of web searches of large populations and compares and analyzes trends by stratifying the results based on geographic location, time period, category, and search type [6]. Google Trends data have proven to be useful in infodemiology research for analyzing human web search behavior about health topics [6]. Information gathered from infodemiology data for infoveillance, such as tracking a surge in web-based misinformation, can be used to identify the need for public health education strategies to counteract the misinformation and provide accurate and up-to-date information [6,7]. Analyzing web search patterns has been used to predict infectious outbreaks, track suicide trends, and identify specific periods of time for effective health promotion campaigns [8-10].

ASD is a complex neurodevelopmental disorder characterized by deficits in communication and social interaction, and restricted and repetitive patterns of behavior [11]. Individuals with ASD exhibit a varied spectrum of symptoms and severity, contributing to the complexity of understanding etiological factors. Although the etiology of ASD is still not fully understood and thought to be multifactorial, research suggests there is a strong genetic basis and/or predisposition in the majority of cases [12,13] and research continues to explore possible nongenetic contributing factors, such as environmental factors, and an interplay between genetic and environmental influences, which may either increase or reduce the risk of ASD [13].

The prevalence of ASD has markedly risen, and it is currently reported to occur in approximately 1 in 54 children [14]. While there is no singular treatment or cure for ASD, early and evidence-based interventions (eg, applied behavior analysis [ABA] strategies) with individualized treatment plans to target goals based on personal strengths, challenges, and needs have been shown to improve developmental outcomes [15].

The high prevalence and complexity of ASD along with the uncertainty surrounding its suspected multifactorial etiology have led to years of searching for answers about causes and looking for effective therapies [16]. While important advances through research have been made, many answers about etiology still remain elusive [16] and, perhaps more than with any other developmental disorder, there is controversy regarding the treatments of ASD [17]. While rigorous research continues to yield evidence-based information, there are many unfounded nonscientific approaches and myths surrounding the causes and treatments of ASD.

The web is a powerful tool for knowledge translation of health information, but it can also amplify alternative or partial truths and misinformation. It is not known which topics surrounding ASD causes and treatments are most frequently searched on the web. Google Trends data have been used to look at seasonal trends in web-based queries about mental health disorders, including ASD [18], and to evaluate the effectiveness of ASD awareness initiatives in promoting web searches on ASD [19]. To our knowledge, however, there are no infodemiology studies looking at trends in web-based queries about the causes and treatments of ASD and how web-based searches have changed over time.

The aim of this study was to use infodemiological data to identify and analyze trends in web-based queries about the causes and treatments of ASD and to evaluate how these trends have changed over the past 15 years. This information could help direct and enrich clinician-patient discussions and aid ASD advocacy and pediatric health organizations in developing web-based knowledge translation interventions and web-based ASD awareness campaigns and education strategies.

Methods

Methodology Framework

The general infodemiology and infoveillance methodology framework for Google Trends analyses, as outlined by Mavragani and Ochoa, was used [6]. This involves a four-step process. The Google Trends analysis tool tracks and quantifies the relative frequency of specific search terms on Google.

Identification of Search Terms

The first step is the identification of search terms. In this study, we selected “autism” instead of “autism spectrum disorder,” as it represents the most comprehensive word to identify ASD.

The search term “autism” was combined with key search terms from questions about the *causes* and *treatments* of ASD commonly raised in the clinical setting.

Web Search Terms for the Causes of ASD

The terms selected for comparative Google Trends analyses for web queries about the causes of ASD were comprised of searches with the term “autism” with key words surrounding topics commonly covered by clinicians and questions commonly raised by parents or caregivers when discussing the cause of ASD. Further, these key words reflect topics and information covered by many ASD or pediatric health organization websites and social media groups. The search terms analyzed included “genetics,” “vaccines,” “environmental factors,” and “microbiome.”

Web Search Terms for the Treatment of ASD

The terms selected for Google Trends analyses for web queries about treatments for ASD were comprised of searches with the term “autism” with key words surrounding topics commonly covered by clinicians and questions commonly raised by parents or caregivers, when discussing intervention for ASD. These key words reflect well-established, popular, emerging, or speculative and/or alternative *therapies* for ASD and reflect topics and information covered by many ASD or pediatric health organization websites and social media groups. The search terms analyzed included “ABA” (applied behavior analysis), “gluten-free diet,” “chelation therapy,” “marijuana,” “probiotics,” and “stem cell therapy.” An additional analysis of the search term of fidget spinners (as they relate to ASD [“autism fidget spinner”]) was also performed in a separate Google Trends analysis, given their high popularity in the recent past and their popular association with disorders such as ASD. This term was analyzed separately as it is not necessarily viewed as an intervention in the same way as the other *intervention* search terms for ASD.

Geographical Region and Time Frame for Analyses

The second step involves selecting the geographical region where the data should be retrieved from, and the third step involves selecting the time frame over which the analyses are conducted. These analyses focused on Google searches in the United States over 15 years from 2004 (the earliest data available for Google Trends analysis) to 2019. Because the analyses spanned a very lengthy period of 15 years, with large amounts of data, the data were aggregated by year (rather than by day or month) for ease of interpretation using the Google Trends mobile app.

Google Trends Search Category for Analyses

The fourth step involves identifying a search category. Categories include options such as Arts & Entertainment, Finance, Food & Drink, Health, Sports, and News, in order to refine the search data analyses. Specifying a category helps to eliminate irrelevant data and to achieve more specific research results. The category of “Health” was used for all search term analyses.

Google Trends Analyses

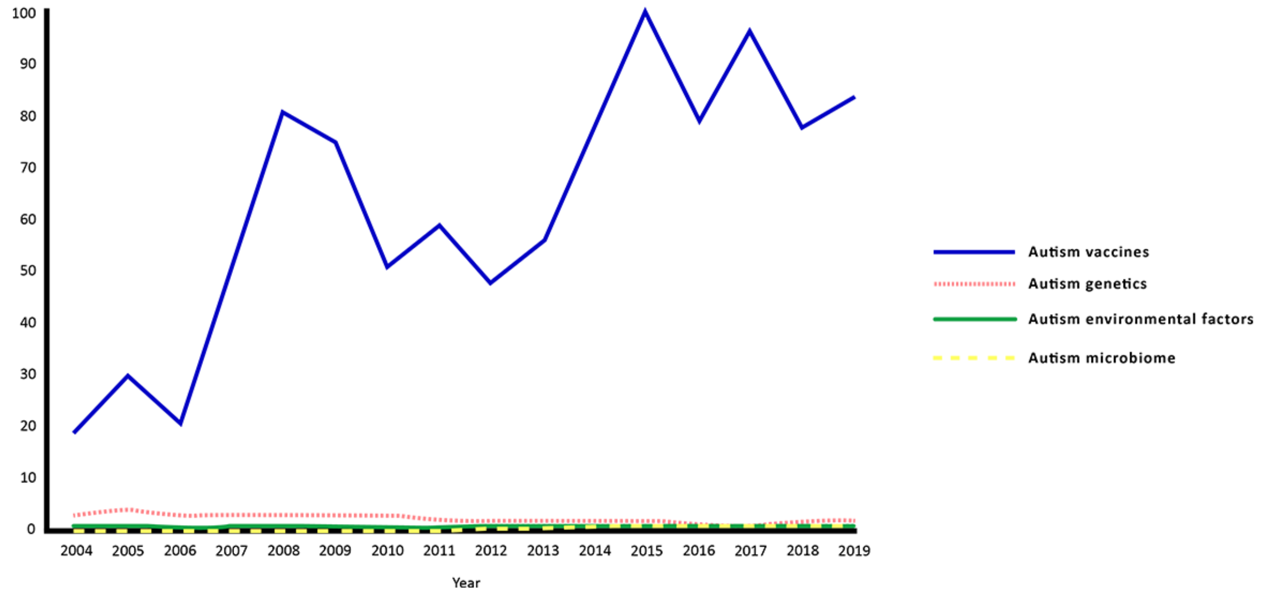
Using Google Trends, each data point is divided by the total searches made within the specified geography region over the specified time range to compare the relative popularity or the relative frequency of specific search terms. More specifically, the relative popularity or frequency of a search term is the ratio of a query’s search volume compared to the sum of the search volumes of all possible Google queries. Queries from the same web-based protocol address made over a short period of time are excluded from results by Google Trends analyses. The data are normalized on a scale ranging from 0 to 100 based on a search topic’s proportion to all searches, making the results comparable [6]. Google Trends algorithms were applied to assess and compare the frequency of the web search terms described, over the specified period (2004-2019) and geographical region (United States), and in the specified category of health.

Results

Web-Based Searches Related to the Causes of ASD

For web-based searches about the causes of ASD using the Google search engine (Figure 1), vaccines had the greatest search volumes when compared with other search terms, with an initial search peak observed in 2008 (scaled score of 81), reaching the maximum and highest search frequency in 2015 (scaled score of 100). There has been continued high interest in the following years, with a scaled score of 84 in 2019 and an upward trend in search interest since 2018 (scaled score of 78).

Figure 1. Google Trends analyses for web searches related to queries about the causes of autism in the United States from 2004 to 2019.



Google search queries about ASD and the role of known or proposed etiological factors, including genetics, environmental factors, and microbiome, occurred relatively and considerably less frequently compared to vaccines (scaled score of 84 in 2019), with minimal overall search interest over the past 15 years and scaled scores of 2, 1, and 1, respectively, in 2019.

Web-Based Searches Related to Therapies for ASD

For web-based searches about therapies for ASD using the Google search engine, ABA consistently had a high frequency of web search interest from 2004 to 2019 (Figure 2), with a slight decrease between 2010 and 2013, followed by a steady rise in search frequency, reaching a maximum scaled score of 100 in 2019.

The analyses of ASD and chelation therapy (Figure 3) showed a precipitous high trending interest in 2005 (scaled score of 68 in 2005 compared to 14 in 2004), followed by a drop in search interest in 2006 (scaled score of 25) and an overall decline in search interest frequency in the following years, with a scaled score of only 10 in 2019.

The analyses of ASD and a gluten-free diet (Figure 3) showed rapid and high trending interest, with a maximum peak search frequency scaled score of 100 in 2007, followed by a steady overall decline in search interest frequency in the years following 2007 and a scaled score of only 16 in 2019.

While searches about ASD and probiotics (Figure 3) have been relatively low over the past 15 years compared to the frequency of other searches for ASD interventions, probiotics appear to be gradually gaining interest, with the highest scaled score over the past 15 years in 2019 (scaled score of 22). Search interest in probiotics and ASD surpassed the frequency of search interest in a gluten-free diet in 2016, which is a nutrition-based intervention that gained popular web search interest in 2007. Web search interest in probiotics and ASD has continued to be more popular than gluten-free diet searches since 2016.

Web searches related to ASD and marijuana (Figure 3) had an initial rise in interest in 2009 (scaled score of 35), possibly coinciding with the legalization and commercialization of marijuana in some jurisdictions [20], and continue to exhibit overall rising popularity in search interest. Apart from searches about ASD and ABA, which have consistently been high (Figure 2), marijuana and ASD have been searched much more frequently than all other intervention search terms evaluated since 2013 (Figure 3).

Web searches regarding ASD and stem cell therapy (Figure 3) have been relatively low, as they represent a topic of more recent research, but they are gradually gaining web search interest, with the highest search frequency in 2019 (scaled score of 18), surpassing the volume of web searches for both gluten-free diet and chelation therapy in 2019.

Google Trends analyses for ASD and fidget spinners were performed separately (Figure 4) as fidget spinners fall into a unique category distinct from intervention or therapy in the traditional sense, but a common topic of interest has been whether they provide any benefits for children with ASD. ASD and fidget spinner searches had a scaled score of 0 prior to becoming popular in the market in 2017. In 2017, fidget spinner searches for ASD had a sudden maximum peak scaled score of 100, followed by a marked drop in search interest in the following 2 years, with scaled scores of 8 and 3 in 2018 and 2019, respectively (Figure 4).

Figure 2. Google Trends analyses for web searches related to queries about applied behavior analysis (ABA) as an intervention for autism in the United States from 2004 to 2019.

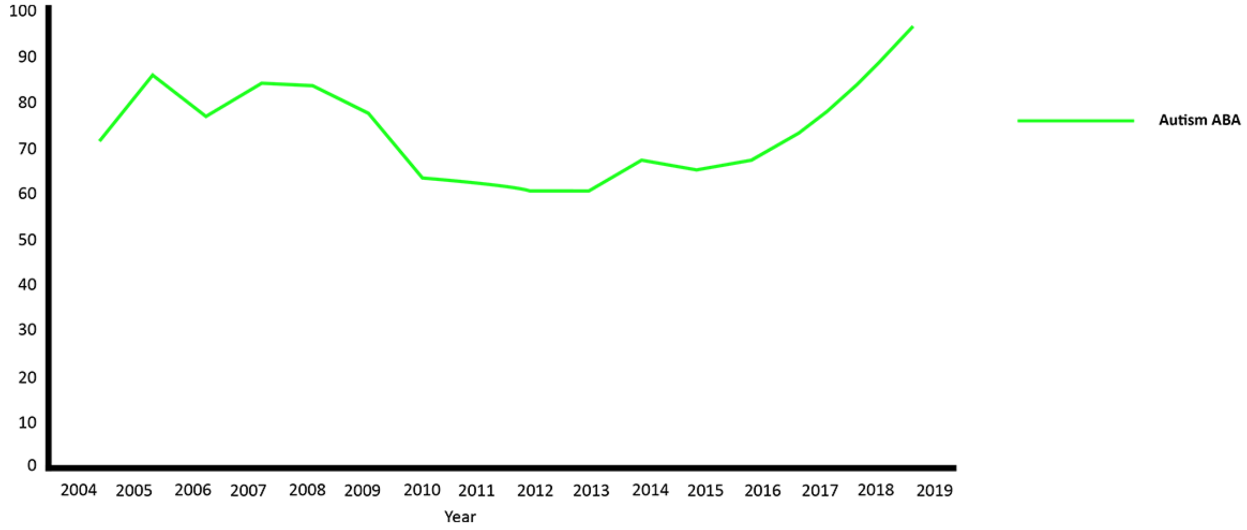


Figure 3. Google Trends analyses for web searches related to queries about interventions for autism in the United States from 2004 to 2019.

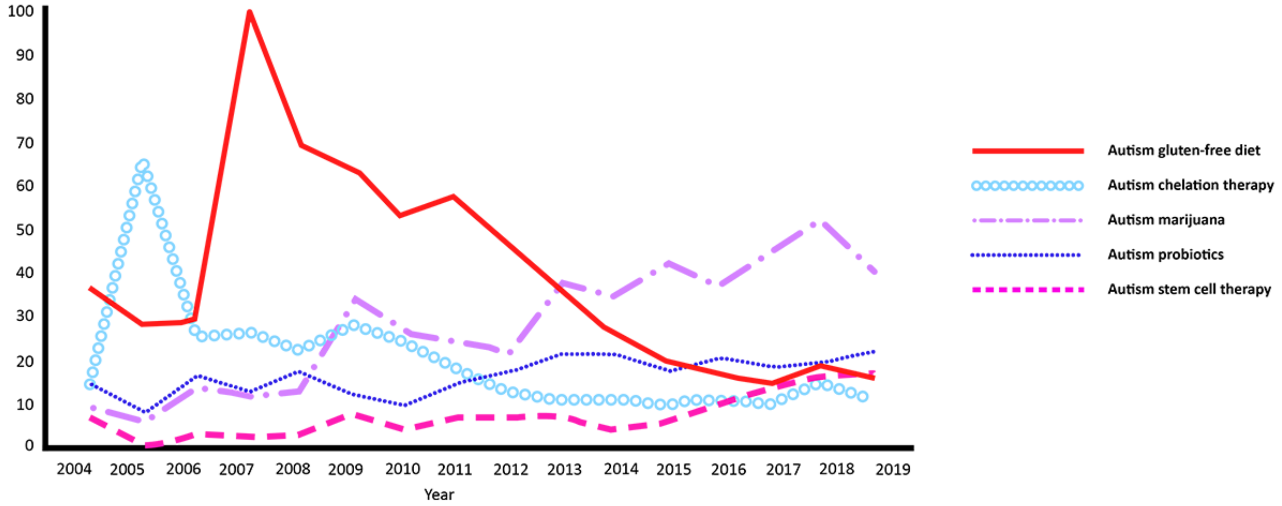
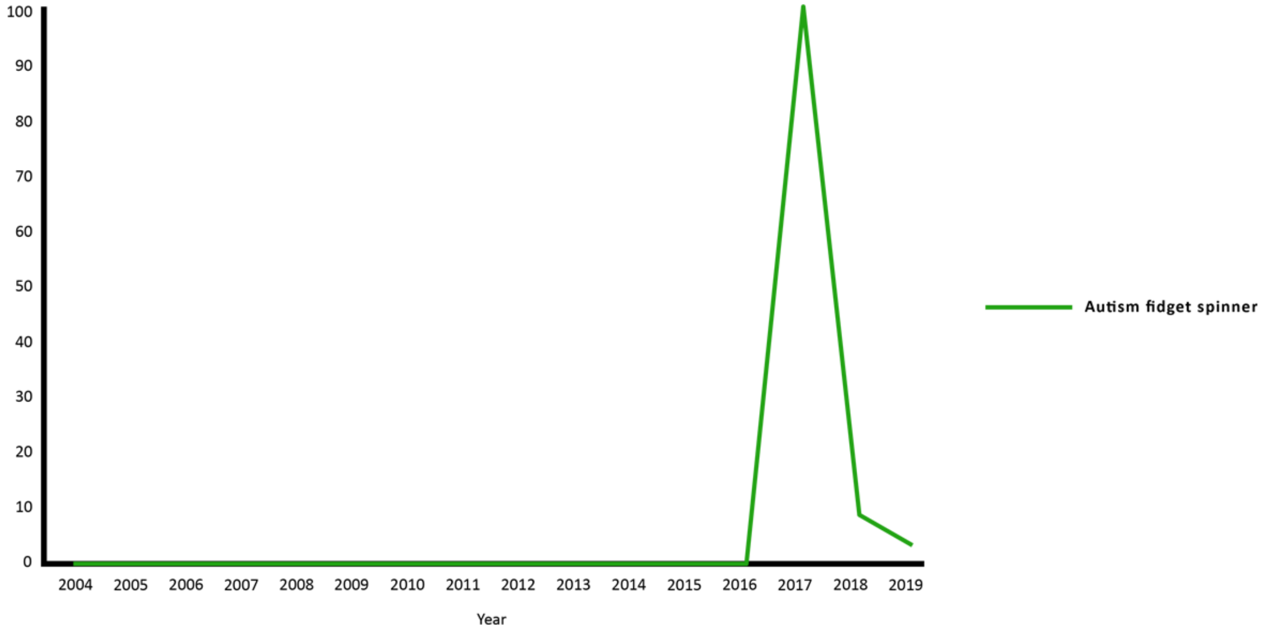


Figure 4. Google Trends analyses for web searches related to queries about autism and fidget spinners in the United States from 2004 to 2019.



Discussion

Principal Findings

Using Google Trends analyses is an effective infodemiology strategy to evaluate large-scale web search data about ASD. These analyses of web searches related to queries about the causes and treatments of ASD showed substantial, variegated, and informative patterns of changes in the frequency of web-based search interest over the past 15 years. Some topics emerged, trended, peaked, and then decreased in search frequency over time, while others remained highly stable topics of public interest demonstrated by a high frequency of web searches over time and still others showed low overall relative interest or are currently gaining public interest. These data provide valuable information and highlight the benefits of the ongoing use of web search analytic tools, as the information yielded can be used to inform clinicians as well as ASD and pediatric health organizations. These data can help guide clinical discussions, as well as education and knowledge translation strategies in order to provide up-to-date and accurate information on relevant topics to improve parent/caregiver, patient, and public awareness about ASD.

ASD and Vaccines, and the Etiology of ASD

Our study confirms that despite the lack of evidence to support vaccines as a cause of ASD [21,22], this topic continues to be the most widely searched web-based topic regarding the cause of ASD on the Google search engine. The initial rise in web-search interest in ASD and vaccines occurred in 2007 and peaked in 2008. Some temporally related factors, which may have contributed to the rise in web searches about autism and vaccines during this time and beyond, were public statements about vaccines and ASD by celebrity Jenny McCarthy and the publication of her books [23,24]. Further, in 2008, Andrew Wakefield admitted to a disciplinary panel that he fabricated details [25] surrounding a study published in the Lancet in 1998 [26] insinuating that the measles, mumps, and rubella (MMR) vaccine may be linked to a risk of ASD. Despite its retraction [27], there was reduced uptake of vaccination and increased concern by parents regarding the vaccination, which was considered by some as a “public health crisis” and “perhaps, the most damaging medical hoax of the last 100 years” [28], and our study showed that relevant public web search interest on the topic of an autism-vaccine connection still continues today. In contrast, Google searches about the genetics of autism, which is believed to play an important role in the etiology of ASD, and possible environmental contributors [12,13,15,16], are relatively much less frequent. These data indicate that web-based content to increase public awareness and parent/caregiver and patient education surrounding the etiological factors of ASD, and vaccinations and ASD continue to be needed.

ASD and ABA Therapy

ABA therapy is considered to be one of the most effective evidence-based interventions for ASD [15]. Our study revealed consistently high volumes of web-based searches over the past 15 years for information about ABA for ASD. This is encouraging as it indicates public awareness of ABA as an intervention for ASD and an interest in learning about this recommended intervention for children with ASD. Further, it highlights the need for ongoing discussions in the clinical setting and accessible web-based information about ABA.

ASD and Chelation Therapy

Chelation therapy is a medical intervention that removes heavy metals from the body. It may be a treatment option to treat metal toxicity due to over exposure or to treat the accumulation of metals, such as iron and copper, that accumulate in the body due to certain medical conditions or diseases. It should only be administered by competent medical professionals. While not recommended as an intervention for ASD [29], it has been used by some as an alternative treatment for ASD [30], based on the unsubstantiated belief that ASD is caused by mercury or thimerosal exposure from vaccination [21]. Thimerosal is a mercury-based preservative that has been used in some vaccinations. According to the Centers for Disease Control and Prevention, the MMR vaccine has never contained thimerosal or mercury [31]. In 1999, it was recommended by the United States Public Health Service that thimerosal be removed as a preservative from childhood vaccines, as a precautionary measure, and “today, no childhood vaccine used in the US, except some formulations of flu vaccine in multidose vials, use thimerosal as a preservative” [31].

Numerous scientific research studies have shown no causal connection between exposure to thimerosal in vaccines and ASD [32-39]. Further, the diagnostic rates of ASD have continued to rise following the precautionary removal of thimerosal from childhood vaccinations [14]. Using chelation therapy as a treatment for children with ASD is not recommended and is in fact considered dangerous as it may lead to serious, harmful, and potentially deadly side effects [17,29].

This study showed that web searches for information about chelation therapy and ASD, which could yield misinformation about its benefits, precipitously rose in 2005, followed by a drop in search interest in 2006 and an overall decline in search interest frequency in the following years, with the lowest web search volumes of all ASD therapies studied. This result is reassuring, as it may reflect a decrease in interest in pursuing this dangerous and ineffective treatment for ASD.

ASD and Nutrition and Gastroenterology

Research suggests that gastrointestinal disturbances are common among children with ASD [40]. This has led to interest in investigating the gut microbiome and a hypothesized microbiota-gut-brain axis in children with ASD [41-43]. Some preliminary investigations have suggested that there may be an imbalance of gut bacteria in some children with ASD [44]. Some researchers have suggested that by alleviating the gastrointestinal response, there could be a behavioral improvement in children with ASD [42]. This study showed that while there is currently a relatively low volume of web-based searches for information about the role of the gut microbiome and ASD, Google searches for information about the use of probiotics for individuals with ASD are on the rise. While some research may suggest that probiotics may have potential for treating gastrointestinal distress in some children, the evidence at this point does not support probiotics as the mainstay of treatment to be used indiscriminately in children with ASD [45,46].

Another alternative nutrition-based intervention that has been commonly linked with ASD is a gluten-free diet [29]. A gluten-free diet is a well-established treatment for individuals with celiac disease, a disorder involving a severe gastrointestinal response to foods containing gluten [47]. However, despite the popular use of a gluten-free diet by parents/caregivers of children with ASD, there is insufficient evidence to indiscriminately recommended it as a treatment for all children diagnosed with ASD [29,48,49]. Web search interest for a gluten-free diet and ASD had gained popularity, with a rapid and high trend, reaching a maximum peak search frequency in 2007. This was however followed by a steady overall decline in web-based search interest frequency in the years following, with relatively low search interest in recent years compared to other ASD interventions. Search interest in probiotics surpassed the frequency of search interest in a gluten-free diet in 2016 and has continued to be a more popular nutrition search term with ASD than a gluten-free diet since 2016. Parents/caregivers of children with ASD are encouraged to discuss their children’s individual nutritional needs with their physicians, as each child’s health, gastrointestinal presentation, and nutritional needs are different.

ASD and Medicinal Marijuana/Cannabis

With changes in legislation and the commercialization of marijuana/cannabis in many regions in North America, there is rising interest in the use of medicinal marijuana for the treatment of various health conditions, including ASD. Web searches related to ASD and marijuana had an initial rise in 2009, coinciding with the commercialization of the legalized use of marijuana in some jurisdictions, and continue to exhibit an overall rising trend in web search popularity. Apart from searches about ASD and ABA (which have consistently been high), marijuana and ASD have been searched much more frequently than all other ASD intervention search terms evaluated since 2013.

The use of medicinal marijuana as a treatment option for children with ASD continues to be a topic of ongoing investigation. There is still a paucity of research and evidence in this area. While research is emerging on the feasibility and possible therapeutic applications [50,51], most research has been limited to observational and retrospective research. At present, there are no known published randomized controlled trials to evaluate the effectiveness, safety, and side-effect profile of the use of medicinal marijuana in children with ASD, or research providing information on their short- and long-term effects, but research is emerging. Autism Speaks, an ASD organization dedicated to advocacy and promotion of solutions for individuals with ASD, recently hosted a scientific consensus conference [52] on identifying the next steps in research on cannabis and autism with the goal of researching safety and potential benefits and developing expert consensus statements on this topic.

ASD and Stem Cell Therapy

Stem cells have regenerative properties, and therefore have potential application in neurological disease. Their application in ASD has been proposed for their potential restorative and immunomodulatory properties that some researchers theorize could lead to better outcomes in children with ASD [53-55]. While theoretical concepts have led to proposals that stem cells may have the potential to be a promising therapy for ASD in the future, there are limitations, and further rigorous research is warranted [55]. Despite the publication of theoretical papers on stem cell therapy applied to ASD, public web search interest on this topic remains low. If future research yields positive promising results and especially if these are highlighted in the media, web search interest on this topic may increase.

ASD and Fidget Spinners

Fidget spinners became popular among children, with a market sales peak in May 2017, accounting for 17% of all online toy sales [56]. At that time, there were considerable web-based claims of their benefits for children with ASD. However, a review of the research concluded that these alleged benefits have not been scientifically proven and that pediatricians should inform parents that these assertions have not been supported by peer-reviewed studies [57]. Not surprisingly, this study showed a surge in the web-based search frequency for fidget spinners and ASD in 2017 during the fidget spinner toy craze, followed by a marked drop in web-based search interest over the past 2 years, and the search term is no longer trending as an area of web-based search interest.

Clinical Applications of Infodemiology Data for ASD

The web is often the first place people look for health information, likely because a search engine is usually more readily accessible [1,3] but it is also possible that some people may feel more comfortable to ask health questions to a search engine than a health professional and/or would like more information. The information from Google Trends analyses can therefore be used to help guide clinicians to open up discussions and create a safe space to ask those questions and enter into a dialogue providing expert, up-to-date, evidence-based information that is specific to a child's unique needs.

The results of this study can be used to guide clinical discussions with parents of children already diagnosed with ASD or receiving a new diagnosis of ASD. This study highlights the fact that people are interested in knowing whether vaccines are associated with ASD, and discussing the research evidence and dispelling any myths surrounding this should be included in counselling when providing a diagnosis of ASD. Further, discussing what is currently known about the genetics of ASD is an area to highlight in counselling parents about etiological factors. Further, there is a great deal of web-based search interest in ABA as a treatment for ASD, and this should be discussed in detail with the parents and caregivers of children with a diagnosis of ASD in order to answer their questions about this intervention and other interventions they may have questions about.

Physicians caring for children with a diagnosis of ASD should always include discussions surrounding nutrition as part of each health visit. They should identify specific nutritional needs and symptoms, answer nutrition questions, and include evidence-based information about nutrition-based treatments for ASD and whether using those nutrition strategies are right and safe for the child's specific nutrition needs. As highlighted in this study, different nutrition treatments have become more and less frequently searched on the web over time. Each child's nutrition, health, and developmental needs are unique, and therefore, advice surrounding this should be part of the health supervision of children with ASD.

As discussed above, there were a number of search topics assessed in this study that still require more rigorous research. Clinicians working with children having ASD should stay abreast of new research evidence and recommendations on such topics. In particular, apart from searches relating to the ABA intervention, searches about the use of marijuana/cannabis in children with ASD have recently been performed more than other web searches for other interventions studied, with an overall upward trend. Research into marijuana/cannabis, the gut microbiome, probiotics, and stem cell therapy may yield more information in the future, and clinicians should be up to date on the research findings in order to answer clinical questions and provide evidence-based recommendations.

Applications of Infodemiology and Infoveillance for Web-Based Knowledge Translation and Education Strategies, and the Use of Microdata Tagging for Search Engine Optimization

The results of this study demonstrate that Google Trends is an effective way to analyze data surrounding public interest of web-based information related to ASD over time and to observe trends in search queries. ASD advocacy organizations who aim to provide up-to-date and topical web-based information about ASD can use such data to monitor public web-based queries about ASD and can use this information to help guide web-based education initiatives. For example, in circumstances such as in 2017, when web searches about fidget spinners and ASD were trending, ASD organizations that provide informational content on their websites could have used such infoveillance data to identify the rise in public queries and guide content on their websites about this topic in order to provide accurate, up-to-date, and evidence-based information on this topic.

ASD and health or pediatric organization webmasters may use the data from this research and Google Trends analyses to adopt more sophisticated website search engine optimization techniques, such as microdata tagging, for helping guide web searches to land on evidence-based information and recommendations. Microdata tagging helps to tell search engines what the components of a webpage are, which can then be highlighted by search engines in web-based search engine queries. For example, ASD and vaccines are highly searched, whereas ASD and genetics are not commonly searched, but they represent important information when discussing the etiology of ASD. Microdata tagging can be used to guide searches about ASD and vaccines to content with evidence-based information about what is known about the etiology of ASD.

Limitations

This study has some limitations that deserve comment. First, Google Trends normalizes data that are represented in a relative scaled score ranging from 0 to 100; however, the total search volume cannot be quantified. Second, these analyses are only able to represent web users and therefore exclude the ability to analyze information from those who do not have internet access, which may bias the results by excluding groups with limited internet access (eg, those with restricted resources and the elderly). Further, it does not capture web-based searches on other search engines; thus, it is not exhaustive. In addition, there are various ways in which this study could have been conducted, and while the search terms analyzed are comprehensive, they are not exhaustive. It should also be mentioned that autism could have been analyzed as either a search term or a topic and the data could have been analyzed specifying the health category or no specified category. Finally, there were no regional differences in web search patterns observed and therefore, maps of regional web searches were not presented in this study. Despite these aforementioned limitations, our results revealed public web-based search patterns in the field of ASD based on large population-based data collection, revealing information over 15 years that is easily accessible and reproducible, with a broad scope.

Conclusions

Using Google Trends is an effective strategy for analyzing infodemiological trends in large-scale web search data about ASD. Analyses of web-based searches related to the causes and treatments of ASD showed variation over the past 15 years. These data provide valuable information that can be used to inform clinicians, and ASD and pediatric health organizations to help guide clinical discussions, web-based content, and education and knowledge translation strategies in order to provide up-to-date and evidence-based information and improve public, parent/caregiver, and patient awareness about ASD.

Conflicts of Interest

None declared.

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Abbreviations

ABA: applied behavior analysis
ASD: autism spectrum disorder
MMR: measles, mumps, and rubella

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Original Paper

Advanced Health Information Technologies to Engage Parents, Clinicians, and Community Nutritionists in Coordinating Responsive Parenting Care: Descriptive Case Series of the Women, Infants, and Children Enhancements to Early Healthy Lifestyles for Baby (WEE Baby) Care Randomized Controlled Trial

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Abstract

Background: Socioeconomically disadvantaged newborns receive care from primary care providers (PCPs) and Women, Infants, and Children (WIC) nutritionists. However, care is not coordinated between these settings, which can result in conflicting messages. Stakeholders support an integrated approach that coordinates services between settings with care tailored to patient-centered needs.

Objective: This analysis describes the usability of advanced health information technologies aiming to engage parents in self-reporting parenting practices, integrate data into electronic health records to inform and facilitate documentation of provided responsive parenting (RP) care, and share data between settings to create opportunities to coordinate care between PCPs and WIC nutritionists.

Methods: Parents and newborns (dyads) who were eligible for WIC care and received pediatric care in a single health system were recruited and randomized to a RP intervention or control group. For the 6-month intervention, electronic systems were created to facilitate documentation, data sharing, and coordination of provided RP care. Prior to PCP visits, parents were prompted to respond to the Early Healthy Lifestyles (EHL) self-assessment tool to capture current RP practices. Responses were integrated into the electronic health record and shared with WIC. Documentation of RP care and an 80-character, free-text comment were shared between WIC and PCPs. A care coordination opportunity existed when the dyad attended a WIC visit and these data were available from the PCP, and vice versa. Care coordination was demonstrated when WIC or PCPs interacted with data and documented RP care provided at the visit.

Results: Dyads (N=131) attended 459 PCP (3.5, SD 1.0 per dyad) and 296 WIC (2.3, SD 1.0 per dyad) visits. Parents completed the EHL tool prior to 53.2% (244/459) of PCP visits (1.9, SD 1.2 per dyad), PCPs documented provided RP care at 35.3% (162/459) of visits, and data were shared with WIC following 100% (459/459) of PCP visits. A WIC visit followed a PCP visit 50.3% (231/459) of the time; thus, there were 1.8 (SD 0.8 per dyad) PCP to WIC care coordination opportunities. WIC coordinated care by documenting RP care at 66.7% (154/231) of opportunities (1.2, SD 0.9 per dyad). WIC visits were followed by a PCP visit 58.9% (116/197) of the time; thus, there were 0.9 (SD 0.8 per dyad) WIC to PCP care coordination opportunities. PCPs coordinated care by documenting RP care at 44.0% (51/116) of opportunities (0.4, SD 0.6 per dyad).

Conclusions: Results support the usability of advanced health information technology strategies to collect patient-reported data and share these data between multiple providers. Although PCPs and WIC shared data, WIC nutritionists were more likely to use data and document RP care to coordinate care than PCPs. Variability in timing, sequence, and frequency of visits underscores the need for flexibility in pragmatic studies.

Trial Registration: ClinicalTrials.gov NCT03482908; https://clinicaltrials.gov/ct2/show/NCT03482908

International Registered Report Identifier (IRRID): RR2-10.1186/s12887-018-1263-z

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KEYWORDS

early obesity prevention; responsive parenting; health information technology; coordination of care; clinical care; pragmatic intervention; data sharing

Introduction

Most lower-income children in the United States receive frequent preventive care, with up to 7 visits in the first 6 months after birth from primary care providers (PCPs) and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) [1-3]. Fragmentation across care settings can lead to inconsistent prevention messages and caregiver confusion [4]. A solution to coordinate care among parents, clinicians, and community health professionals is needed [4]. Stakeholders are aligned in their support of a solution that both personalizes messaging to meet parents' time-sensitive needs on infant development and integrates relevant data to coordinate care across settings and break down silos [4]. The perceived benefits of personalization, integration, and care coordination, according to stakeholders, include improved child health outcomes and reduced duplication of efforts [4].

From a preventive health model perspective, the need to collect and share data among patients and clinical and community health professionals aligns with a series of reports [5-9] calling for systems approaches through the integration and coordination of care across service settings [9,10]. Integrated and coordinated care approaches are commonly applied within the clinical sector [11-13] (eg, general physicians and specialists), but given the capabilities and demonstrated benefits of advanced health information technologies (HITs) [12,13], the contemporary calls aim to extend these approaches to public health, community settings, and patients. In particular, the Chronic Care Model and the Culture of Health Action Framework emphasize connectivity and integration of public health, clinical services, and social services to advance quality, health outcomes, and equity, specifically for vulnerable populations [14,15].

The integrated and coordinated care model described in this paper applied advanced HIT strategies and represents a novel cross-sector care delivery model to address patient-centered care [11,16]. As little is known about the feasibility of cross-sector delivery models, this study addresses a gap by applying and evaluating the usability of advanced HIT capabilities to engage patients and clinical and community providers in a broader patient-centered, integrated, and coordinated care process. The intervention arm of the WIC Enhancements to Early Healthy Lifestyles for Baby (WEE Baby) Care Study aimed to integrate and coordinate care on responsive parenting (RP) guidance related to feeding, sleep, and play. The intervention was based on an evidence-based program that included messages that mothers believe should be a part of pediatric or WIC care [17-19]. The objective of this paper is to demonstrate the usability of advanced HIT strategies designed to engage parents in reporting RP practices, integrate data into electronic records to inform and facilitate documentation of provided RP care, and share data between settings to facilitate coordination of care between PCPs and WIC. The findings are intended to inform and advance novel cross-sector delivery models conceptualized to improve patient-centered care and health outcomes. While health outcomes are beyond the scope of this paper, these findings will inform the feasibility of models that align organizational resources and integrate activities for collective impact on population health objectives.

Methods

Study Design

The integrated and care coordination delivery model was constructed for the WEE Baby Care Study, which has been described elsewhere [20]. Briefly, the WEE Baby Care Study was a pragmatic trial to modify maternal parenting practices, with the goal of preventing rapid infant weight gain and obesity. Mothers and their newborn infants were assigned to either a 6-month RP intervention group (n=131) that included advanced HIT strategies to integrate and coordinate care between pediatric PCPs and WIC nutritionists or a control group (n=157) receiving standard care [20]. This analysis is limited to the 131 mother-infant dyads who were enrolled in the intervention group in which advanced HIT strategies were applied to collect patient-reported data, use these data to inform patient-centered care, securely share data, and coordinate care between PCPs and WIC nutritionists.

Participants and Recruitment

From July 2016 to May 2018, mother-infant dyads were recruited and enrolled from northeastern Pennsylvania, an area characterized by the Health Services and Resources Administration as medically underserved, with shortages in health, dental, and mental health professionals [21]. Mother-infant dyads were either recruited in person in the labor and delivery unit or on the phone after the first well-child visit (WCV). Eligible dyads met the following inclusion criteria: full-term (≥37 weeks gestation) infant, singleton newborn, English-speaking mother between 18 and 55 years old, intention to receive well-child care at a participating pediatric clinic, and eligibility to be enrolled in or current enrollment in WIC. Participants provided written informed consent. All study procedures were approved by the institutional review boards of The Pennsylvania State University and Geisinger.

Intervention and Advanced HIT Strategies

Mother-infant dyads randomized into the intervention group completed the Early Healthy Lifestyles (EHL) risk assessment tool prior to each WCV. The study team developed the EHL risk assessment tool to facilitate mothers' self-assessments of their RP practices related to feeding, soothing, and playing with the infant, as well as the infant's sleep behaviors. The parent was prompted by electronic messaging to complete the EHL in the patient portal prior to the WCV. The mother's proxy access to the child's portal was ensured at study enrollment. If the parent did not complete the tool, clinic staff encouraged the parent to complete the EHL in the waiting room on a tablet. Parent responses were then instantly integrated into the infant's electronic health record (EHR) (Epic Systems).

Within the WCV progress note, PCPs could view and use the EHL data to inform and document patient-centered RP care. Prior to the start of the intervention, participating PCPs were trained to evaluate the EHL data, deliver tailored RP messages that aligned with parent learning needs at WCVs, and document provided RP care in the study-specific table in the WVC progress note, herein referred to as the PCP system. Age-appropriate, preventive messages were informed by the Intervention Nurses Start Infants Growing Healthy Trajectories (INSIGHT) study and American Academy of Pediatrics Healthy Active Living for Families curriculum [17,22,23]. PCPs used progress note functions to facilitate documentation of RP care provided during the WCV. Additionally, PCPs could add an 80-character, free-text comment to send to the WIC nutritionist, perhaps to direct attention to a high-priority issue. No action by the PCP was required to initiate data sharing. Development of the PCP system was guided, approved, and integrated into the EHR by Geisinger's Health Information Technology Team.

Advanced HIT strategies were used to automate and securely share data of interest (Textbox 1) from the PCP to WIC, including parent EHL responses, PCP documentation of RP care, and child physical assessment. In turn, these data were automatically integrated and displayed in a study-specific system (herein referred to as the WIC system) to inform patient-centered counseling as coordinated care in the community setting. The WIC system was separate from WIC's standard electronic participant management system—QuickWIC, a HTML system developed in the late 1990s—and could be used in parallel. Separate log-ins were required for each system. WIC nutritionists documented RP care in QuickWIC and comments in the WIC system. The WIC system extracted education codes from QuickWIC. Following the visit with the trained WIC nutritionist, encounter data of interest (Textbox 1) were extracted from the WIC system and securely shared from WIC to the PCP, thus providing a communication feedback loop to coordinate care at subsequent visits. Uniquely, the WIC system required the nutritionist to sign off on the record after the visit was completed to initiate data sharing. WIC nutritionists received training on this process, the use of EHL data, and the delivery of RP care messages prior to the start of the intervention. A booster training session was provided in the 14th month of the intervention. Data were exchanged between the PCP system and the WIC system through a secure file transport portal managed by the clinical care setting study team, and data were refreshed on weekdays. This process continued for a 6-month period to allow multiple opportunities for care coordination using shared data across clinic and community settings. Figure 1 provides an overview of the flow for patient-reported data collection, integration, sharing, and care coordination. An application developer at the Pennsylvania Department of Health developed and implemented the WIC system as an external cloud system as opposed to an integrated system, as statewide plans were underway to replace the QuickWIC system.

Attendance of WCVs and WIC visits was not mandatory or incentivized in this pragmatic study but was necessary for data of interest to be collected. The typical WCV schedule for infants within the health system includes visits at 3 to 5 days (newborn), 1 month, 2 months, 4 months, and 6 months of age. The study team expected that the intervention participants would attend at least 4 WCVs. To receive WIC benefits, infants and their mothers enrolled in WIC need to have a visit every 3 months; thus, the study team expected intervention participants would attend at least 2 WIC visits. In sum, this would allow multiple opportunities for care coordination between PCPs and WIC.

Textbox 1. Existing and study-specific systems with associated data elements shared by pediatric primary care providers from well-child visits and the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) nutritionists from appointments to inform care coordination. Italics indicate essential data elements for data set used for coding of data sharing, care coordination opportunity, and care coordination. Infant date of birth and enrollment date were extracted from the research team's records.

Data from pediatric clinics

Existing electronic health record:

- *Date of well-child visit*
- *Weight and length*
- *Immunizations*
- Demographics
- Hemoglobin and hematocrit
- Encounter and problem list
- Diagnoses
- Breastfeeding status
- Formula use

Study-specific primary care provider system integrated into electronic health record:

- *Parent completion of Early Healthy Lifestyles risk assessment*
- *Date that Early Healthy Lifestyles risk assessment was completed by parent*
- *Primary care provider documentation of Early Healthy Lifestyles preventive counseling*
- *Primary care provider comment to WIC nutritionist*

Data from WIC clinics

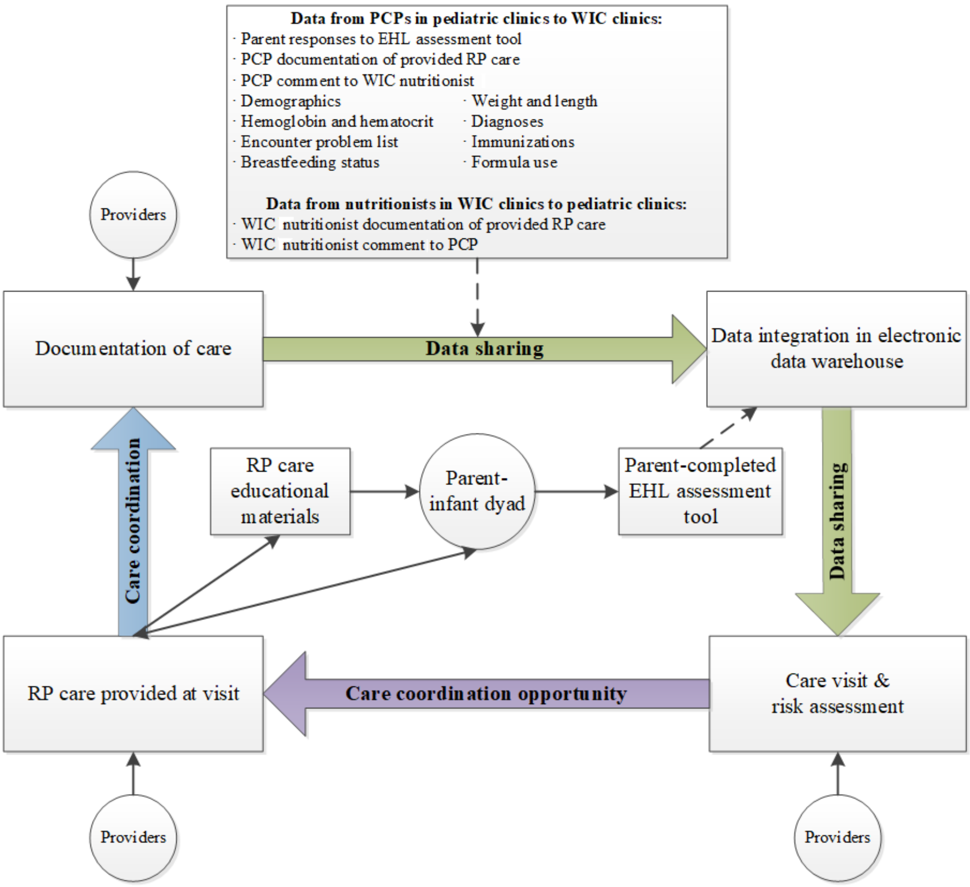
Existing QuickWIC system:

- *Date of WIC visit*
- *Date that nutritionist documented responsive parenting preventive care*
- *Nutritionist documentation of responsive parenting preventive care. The WIC nutritionist documented responsive parenting preventive care with standard WIC topic codes, as well as codes developed for the study.*

Study-specific WIC system:

- *Nutritionist comment to primary care provider*
- *Nutritionist sign-off on record*
- *Date of nutritionist sign-off*

Figure 1. WEE Baby Care Study data flow for collection from parents, use by providers, and sharing for care coordination between clinic and community settings. EHL: Early Healthy Lifestyles; PCP: primary care provider; RP: responsive parenting; WIC: Special Supplemental Nutrition Program for Women, Infants, and Children.



Outcome Definitions

The outcomes of interest included the use of the advanced HIT strategies and the feasibility of data sharing and care coordination occurring in 2 directions, from PCPs to WIC and from WIC to PCPs. Data sharing is the electronic and systematic push of study-related data through the electronic data warehouse (distinct from the EHR and PCP system) managed by the research team in the clinical setting. Data sharing does not require the PCP or WIC nutritionist in the receiving setting to interact with the data of interest (Textbox 1).

A care coordination opportunity is nested within data sharing and is an opportunity for a PCP or WIC nutritionist to view data for the most recent visit from the sending setting. Due to the secure and study staff–dependent data sharing processes, the receiving provider was able to view the shared data within 2 business days if sent by the PCP and 1 business day if sent by the WIC nutritionist. Eligible WCVs occurred after the dyad was enrolled into the study and continued up to 6 months of the infant's age, at which time the clinical study team turned off the PCP system. Eligible WIC visits occurred after the dyad was enrolled in the study but before disabling the PCP system.

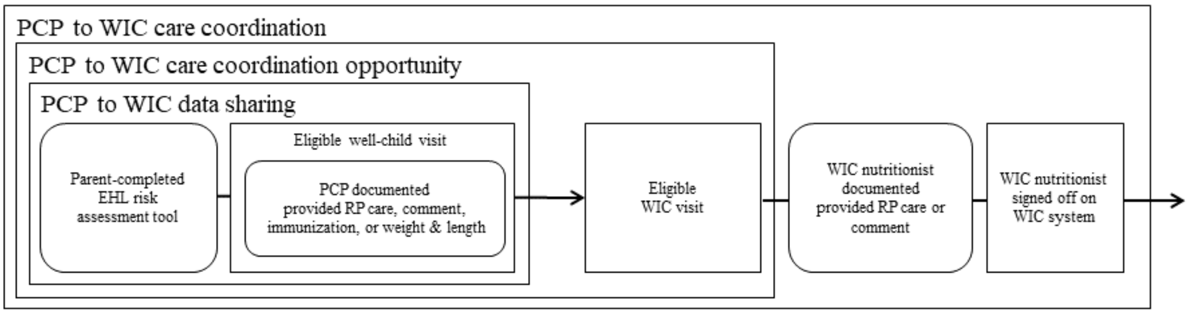
Care coordination is nested within a care coordination opportunity and requires a PCP or WIC nutritionist in the receiving setting to be able to access the sent data and document the provided RP care. The study team could not directly verify that the receiving setting interacted with the sent data, as accessing or viewing the data was not captured with a discrete data point; thus, the documentation of RP care serves as proxy evidence that the receiving provider used the shared data to coordinate care. Preventive RP care included educational messages that addressed parent learning needs as self-assessed by parents using the EHL tool. Preventive RP care was documented by PCPs and WIC nutritionists by selecting RP topics, writing a free-text comment, or both.

Coding of Outcomes

The coding process was operationally detailed in a study team–developed coding manual that was extensively reviewed multiple times by 5 study team members (SMRK, HAH, MM, JSS, and LBD) and applied to a comprehensive, single data set. The data set included data from the PCP system and the WIC system along with other data elements listed in Textbox 1 to identify data sharing, care coordination opportunities, and care coordination outcomes. Two postdoctoral-level study team members (SMRK and HAH) coded the data independently, discrepancies were discussed and resolved using the coding manual, and both team members recoded the discrepant observations. After the first round of coding, 86% of coded observations agreed between the two coders, demonstrating adequate understanding of the coding process. This process continued until the 2 sets of coded data completely matched.

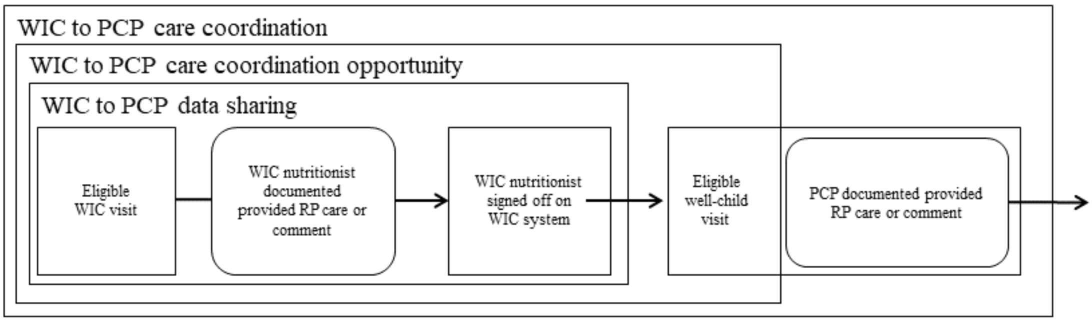
PCP to WIC data sharing, care coordination opportunities, and care coordination events were identified. The criteria for these outcomes are depicted in Figure 2. PCP to WIC data sharing required an eligible WCV to have at least one of the following data points documented: (1) parent-completed EHL, (2) documentation of RP care provided by the PCP, (3) PCP comment to WIC, (4) immunization records, or (5) weight and length. After the identified PCP to WIC data sharing occurrence, a PCP to WIC care coordination opportunity occurred when the WCV was followed by an eligible WIC visit that occurred two or more business days after the WCV to allow ample time for the shared data to be available in the WIC system for the nutritionist. Subsequently, a PCP to WIC care coordination event was identified when the WIC nutritionist documented provided RP care or commented to the PCP and signed off on the record.

Figure 2. Components of data sharing, care coordination opportunities, and care coordination from pediatric PCPs to WIC nutritionists. EHL: Early Healthy Lifestyles; PCP: primary care provider; RP: responsive parenting; WIC: Special Supplemental Nutrition Program for Women, Infants, and Children.



WIC to PCP data sharing, care coordination opportunities, and care coordination events were identified. As shown in Figure 3, WIC to PCP data sharing occurred when an eligible WIC visit had (1) documentation of RP care provided by the nutritionist or (2) a nutritionist comment or comments to the PCP, in addition to (3) a nutritionist sign-off on the same day or after the WIC visit. After the identified WIC to PCP data sharing occurrence, a WIC to PCP care coordination opportunity was identified when the WIC sign-off date was directly followed by a WCV to allow for shared data to be available in the PCP system for the PCP. Subsequently, a WIC to PCP care coordination event was identified when the PCP documented EHL-related preventive counseling or commented to WIC on the same day as the WCV.

Figure 3. Components of data sharing, care coordination opportunities, and care coordination from WIC nutritionists to pediatric PCPs. PCP: primary care provider; RP: responsive parenting; WIC: Special Supplemental Nutrition Program for Women, Infants, and Children.



Statistical Analysis

All data were processed and analyzed using SAS (version 9.4; SAS Institute Inc). The SAS functions “Proc Freq” and “Proc Means” were used to describe the sample and determine the total number and mean per dyad (with standard deviation) of variables of interest to describe the usability of the advanced HIT technologies and feasibility of data sharing and care coordination using the coded variables described above.

Results

Participants

As shown in Table 1, 49.6% (65/131) of infants were male and 67.7% (88/131) were White. Mothers were aged 27.7 (SD 5.7) years at the time of infant delivery, and 26.0% (34/131) were primiparous. Infants were enrolled at 0.34 (SD 0.43) months of age. Most mothers were White, single, had an income less than $50,000, and had at least a high school diploma.

Table 1. Demographic characteristics of mothers and infants who were assigned to a parenting intervention (N=131) that used advanced health information technology strategies to integrate and coordinate care in the WEE Baby Care Study.

Demographic characteristic	Responsive parenting intervention mother-infant dyads (N=131)
Infant	
Male, n (%)	65 (49.6)
Gestational age (weeks), mean (SD)	39.7 (1.1)
Birth weight (kg), mean (SD)	3.47 (0.43)
Birth length (cm), mean (SD)	49.2 (2.3)
Age at enrollment (months), mean (SD)	0.34 (0.43)
Infant race, n (%)	
Black	22 (16.9)
White	88 (67.7)
American Indian or Alaskan Native	0 (0.0)
Asian	1 (0.8)
Other	19 (14.6)
Mother	
Age at infant birth (years), mean (SD)	27.7 (5.7)
Diabetes during pregnancy, n (%)	20 (16.1)
Smoked during pregnancy, n (%)	26 (21.0)
Hispanic, n (%)	26 (21.1)
Primiparous, n (%)	34 (26.0)
Marital status, n (%)	
Married	25 (20.2)
Not married, living with partner	34 (27.4)
Single	57 (46.0)
Divorced or separated	6 (4.8)
Widowed	0 (0.0)
Other	2 (1.6)
Annual household income (US $), n (%)	
<10,000	28 (22.6)
10,000-24,999	52 (41.9)
25,000-49,999	30 (24.2)
50,000-74,999	3 (2.4)
Do not know	8 (6.5)
Refuse to answer	3 (2.4)
Education, n (%)	
Some high school or less	13 (10.5)
High school graduate	60 (48.4)
Some college	41 (33.1)
College graduate	9 (7.3)
Graduate degree or greater	1 (0.8)

Use of Advanced HIT Strategies

The 131 intervention mother-infant dyads attended 459 eligible WCVs and 296 eligible WIC visits throughout the observation period; thus, participants attended over 3 (mean 3.5, SD 1.03) WCVs per dyad on average and over 2 (mean 2.26, SD 0.97) WIC visits per dyad on average (Table 2). Of the expected 4

WCVs and 2 WIC visits per dyad to be experienced in the observation period, 45.8% (60/131) of dyads attended 4 or more WCVs and 78.6% (103/131) attended 2 or more WIC visits.

Mothers completed the EHL risk assessment 262 times (mean 2.0, SD 1.23) (Table 3). Of the expected EHL completions prior to a WCV, 10.7% (14/131) of dyads completed 4 or more EHL risk assessments, but 16.0% (21/131) did not complete a single EHL assessment.

PCPs used the PCP system to document RP care at least once (mean 1.37, SD 1.30) per participant but almost never wrote a comment to the nutritionist (mean 0.02, SD 0.15 comments per participant). Of the expected 4 or more WCVs, PCPs documented RP care for 6.9% (9/131) of dyads, but 35.1% (46/131) of participants did not have any RP care documented by the PCP. Anthropometric measures and immunization data were routinely available in the infants' EHR (Table 4).

Nutritionists documented RP care at least twice per participant (mean 2.21, SD 0.82) (Table 3). Nutritionist comments to PCPs were provided at least once per participant (mean 1.5, SD 0.96). Of the expected 2 or more WIC visits, nutritionists documented RP care for 81.6% (107/131) of dyads and comments for 46.5% (61/131) of dyads; 1.5% (2/131) and 14.5% (19/131) of dyads did not any have documentation of RP care or a nutritionist comment to the PCP, respectively. Nutritionists used the WIC system to sign off on a single record per participant (mean 1.64, SD 1.03). Of the expected 2 or more WIC visits, slightly over half of dyads (71/131, 54.1%) had a sign-off from the nutritionist in the WIC system, but 32.8% (43/131) and 13.0% (17/131) of participants only had 1 or no sign-offs, respectively, which prevented WIC to PCP data sharing and data coordination opportunities.

Table 2. Total number and average per participant of data sharing, care coordination opportunities, and care coordination events between clinic and community settings for 131 mother-infant dyads in the WEE Baby Care Study.

Event	Totals for intervention sample (N=131)	Descriptive statistics for intervention participants	
	Events, n (%)	Mean (SD)	Range
Clinic WCV[a,b]	459	3.50 (1.03)	1-7
Community WIC[c,d] visits	296	2.26 (0.97)	0-5
PCP to WIC data sharing and care coordination			
PCP to WIC data sharing	459	3.50 (1.03)	1-7
with length and weight measures	457 (99.6)	3.49 (1.02)	1-7
with immunization records	231 (50.3)	1.76 (0.70)	0-3
with Early Healthy Lifestyles risk assessment	244 (53.2)	1.86 (1.15)	0-4
with PCP[e] documentation of provided RP[f] care	162 (35.3)	1.24 (1.19)	0-4
with PCP comment to WIC nutritionist	3 (0.7)	0.02 (0.15)	0-1
PCP to WIC care coordination opportunity	231	1.76 (0.81)	0-3
with length and weight measures	231 (100.0)	1.76 (0.81)	0-3
with immunization records	137 (59.3)	1.05 (0.63)	0-3
with Early Healthy Lifestyles risk assessment	134 (58.0)	1.02 (0.86)	0-3
with PCP documentation of provided RP care	88 (38.1)	0.67 (0.72)	0-3
with PCP comment to WIC nutritionist	1 (0.4)	0.008 (0.09)	0-1
PCP to WIC care coordination	154	1.18 (0.85)	0-3
with length and weight measures	154 (100.0)	1.18 (0.85)	0-3
with immunization records	86 (55.8)	0.66 (0.85)	0-2
with Early Healthy Lifestyles risk assessment	84 (54.5)	0.64 (0.76)	0-3
with PCP documentation of provided RP care	57 (37.0)	0.44 (0.61)	0-3
with PCP comment to WIC nutritionist	1 (0.6)	0.008 (0.09)	0-1
with WIC documentation of provided RP care	153 (99.4)	1.15 (0.84)	0-3
with WIC nutritionist comment to PCP	144 (93.5)	1.10 (0.81)	0-3
WIC to PCP data sharing and care coordination			
WIC to PCP data sharing	197	1.50 (0.95)	0-4
with WIC documentation of provided RP care	193 (98.0)	1.47 (0.91)	0-4
with nutritionist comment to PCP	183 (92.9)	1.40 (0.91)	0-4
WIC to PCP care coordination opportunity	116	0.89 (0.78)	0-3
with WIC documentation of provided RP care	114 (98.3)	0.87 (0.78)	0-3
with nutritionist comment to PCP	106 (91.4)	0.81 (0.73)	0-3
WIC to PCP care coordination	51	0.39 (0.58)	0-2
with WIC documentation of provided RP care	50 (98.0)	0.38 (0.56)	0-2
with nutritionist comment to PCP	48 (94.1)	0.37 (0.56)	0-2
with PCP documentation of provided RP care	51 (100.0)	0.39 (0.58)	0-2
with PCP comment to WIC nutritionist	1 (2.0)	0.008 (0.09)	0-1

[a] WCV: well-child visit.

[b] Of the expected 4 WCVs to be attended by the dyad in the intervention period, 45.8% (60/131) of dyads attended 4 of more WCVs.

[c] WIC: Special Supplemental Nutrition Program for Women, Infants, and Children.

[d] Of the expected 2 WIC visits to be attended by the dyad in the intervention period, 77.9% (103/131) of dyads attended 2 or more WIC visits.

[e] PCP: primary care provider.

[f] RP: responsive parenting.

Table 3. Total number and average per individual participant of intervention components derived from clinical and community settings for 131 mother-infant dyads in the responsive parenting intervention arm of the WEE Baby Care Study.

Intervention component	Frequency for total sample (N=131)	Descriptive statistics for intervention participants	
	Total Events, n	Mean (SD)	Range
Clinical intervention components from WCV[a]			
Infant length and weight measures	665	5.08 (2.01)	1-15
Immunization records	296	2.26 (0.83)	0-4
Early Healthy Lifestyles (EHL) risk assessment	262	2.00 (1.23)	0-5
PCP[b] documentation of provided RP[c] care	180	1.37 (1.30)	0-4
PCP comment to WIC nutritionist	3	0.02 (0.15)	0-1
Community intervention components from WIC[d]			
Nutritionist documentation of provided RP care	289	2.21 (0.82)	0-4
Nutritionist comment to PCP	196	1.50 (0.96)	0-4
Nutritionist signed off in WIC system[e]	215	1.64 (1.03)	0-6

[a] WCV: well-child visit.

[b] PCP: primary care provider.

[c] RP: responsive parenting.

[d] WIC: Special Supplemental Nutrition Program for Women, Infants, and Children.

[e] WIC system: study-specific system that allowed nutritionists to sign off on study activity to share data.

Table 4. Frequency distributions of intervention components derived from clinical and community settings for 131 mother-infant dyads in the responsive parenting intervention arm of the WEE Baby Care Study.

Component	Number of times event occurred, n (%)							
	0 times	1 time	2 times	3 times	4 times	5 times	6 times	7+ times
Clinical intervention components from WCV[a]								
Length and weight measures	1 (0.7)	6 (4.6)	13 (9.9)	41 (31.3)	27 (20.6)	18 (13.7)	11 (8.4)	14 (10.7)
Immunization records	3 (2.3)	15 (11.5)	66 (50.4)	39 (29.8)	8 (6.1)	0 (0.0)	0 (0.0)	0 (0.0)
Early Healthy Lifestyles risk assessment	21 (16.0)	20 (15.3)	43 (32.8)	33 (25.2)	13 (9.9)	1 (0.7)	0 (0.0)	0 (0.0)
PCP[b] documentation of provided RP[c] care	46 (35.1)	30 (22.9)	24 (18.3)	22 (16.8)	9 (6.9)	0 (0.0)	0 (0.0)	0 (0.0)
PCP comment to WIC nutritionist	128 (97.7)	3 (2.3)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Community intervention components from WIC[d]								
Nutritionist documentation of provided RP care	2 (1.5)	22 (16.8)	59 (45.0)	43 (32.8)	5 (3.8)	0 (0.0)	0 (0.0)	0 (0.0)
Nutritionist comment to PCP	19 (14.5)	51 (38.9)	39 (29.8)	21 (16.0)	1 (0.7)	0 (0.0)	0 (0.0)	0 (0.0)
Nutritionist signed off in WIC system[e]	17 (13.0)	43 (32.8)	45 (34.4)	24 (18.3)	1 (0.7)	1 (0.7)	0 (0.0)	0 (0.0)

[a] WCV: well-child visit.

[b] PCP: primary care provider.

[c] RP: responsive parenting.

[d] WIC: Special Supplemental Nutrition Program for Women, Infants, and Children.

[e] WIC system: study-specific system that allowed nutritionists to sign off on study activity to share data.

Feasibility of Data Sharing and Care Coordination

PCP to WIC data sharing occurred for all 459 (100%) WCVs (Table 2). Almost all events (257/259, 99.6%) included the infant's length and weight, and half included immunization records (231/459, 50.3%) and parent responses to EHL assessment (244/459, 53.2%). One-third of PCP to WIC data sharing events (162/459, 35.3%) included documentation of PCP RP care; thus, one event per dyad had PCP documentation (mean 1.24, SD 1.19). Very few events (3/459, 0.7%) had a PCP comment to the WIC nutritionist. A WIC visit followed 231 of the 459 (50.3%) PCP to WIC data sharing events; thus, dyads averaged less than 2 (1.7, SD 0.81) PCP to WIC care coordination opportunities (Table 2). All (231/231, 100%) PCP to WIC care coordination opportunities included the infant's length and weight, slightly more than half included immunization records (137/231, 59.3%) and EHL responses (134/231, 58.0%), and about one-third (88/231, 38.1%) included PCP documentation of RP care.

PCP to WIC care coordination was evident in 154 of 231 (66.7%) of PCP to WIC care coordination opportunities; thus, dyads averaged at least one PCP to WIC care coordination event (1.18, SD 0.85) (Table 2). WIC nutritionists were able to view anthropometric measures at all care coordination events (154/154, 100%), immunization records at 55.8% (86/154) of events, parent EHL responses at 54.5% (84/154) of events, and PCP documentation of RP care at 37.0% (57/154) of care coordination events. Dyads, on average, had few events that included their EHL responses (mean 0.64, SD 0.76) and PCP documentation of RP care (mean 0.44, SD 0.61), thus limiting opportunities for nutritionists to use EHL data and PCP RP care to inform care and coordinate with PCPs. To coordinate care, however, the trained WIC nutritionists documented RP counseling (153/154, 99.4%) and commented (144/154, 93.5%) at nearly all events; therefore, on average, each dyad received EHL-related RP preventive counseling from a WIC nutritionist one time (1.15, SD 0.84). Of the 231 care coordination opportunities, the 77 missed opportunities were primarily due to a missing record sign-off, as WIC nutritionists consistently documented RP care.

Given the bidirectional flow of care and data, intervention components and outcomes were also evaluated from WIC to PCPs as events independent from PCP to WIC care coordination. Data sharing from WIC to PCPs occurred for 197 of 296 (66.6%) WIC visits (Table 2). Nearly all WIC visits included documented EHL-related preventive counseling (193/197, 98.0%) or comments to the PCP (183/197, 92.9%). A WCV followed 116 of the 197 (58.9%) WIC to PCP data sharing events; thus, dyads averaged just under 1 (0.89, SD 0.78) WIC to PCP care coordination opportunity. The majority of WIC to PCP care coordination opportunities included documentation of RP preventive counseling (114/166, 98.3%) and comments to the PCP (106/166, 91.4%). At 51 of 116 (44.0%) WIC to PCP care coordination opportunities, PCPs documented RP preventive counseling (51/51, 100%) or a comment (1/51, 2.0%) to the nutritionist to coordinate care; thus, dyads averaged few (0.39, SD 0.58) WIC to PCP care coordination events. PCPs were able to view nutritionist documentation of RP preventive counseling (50/51, 98.0%) and comments (48/51, 94.1%).

Discussion

This study suggests that advanced HIT strategies are a potential solution to engage parents in reporting RP practices, integrate data into the infant's electronic patient management systems to inform and facilitate documentation of provided RP care, and share data between PCPs and WIC nutritionists serving socioeconomically disadvantaged parents and infants from an area with known shortages in health care services. Even though bidirectional data sharing was feasible, care coordination occurred less frequently. Typically, these advanced HIT strategies are commonly found and siloed in larger health systems with standardized EHRs, a resource supported by policy and practice [11-13]; however, the current study applied advanced HIT strategies to bidirectionally share data across local community and clinical settings, an important step in coordinating patient-centered preventive care. Implemented strategies used to collect, integrate, and share data were adopted by patients, PCPs, and WIC nutritionists, suggesting usability, but variable utilization of certain components inhibited care coordination. Replication and dissemination of a cross-sector model may be facilitated by clinical partners practicing in a standardized EHR environment, with these findings providing foundational lessons and recommendations for future iterations.

Observed data sharing between clinic and community settings demonstrated usability, yet PCP to WIC data sharing occurred at more than twice the rate of WIC to PCP data sharing, likely mirroring the more frequently scheduled and attended WCVs relative to WIC visits. The infrastructure and processes developed to share data between PCPs and WIC differed in reliability and efficiency. PCP to WIC data sharing functioned more reliably than in the reverse direction. Data elements were passively extracted from EHRs without PCP action beyond standard documentation and thus were reliably (459/459, 100%) shared with WIC after the WCVs. In comparison, WIC to PCP data sharing was less reliable (197/296, 66.6%), as the process required the WIC nutritionist to sign off in the WIC system, a step that was missed for one-third of events, impacting usability. In addition, this extra step in the nutritionists' workflow was critical for PCP to WIC care coordination, as a sign-off on the WIC system was required to complete the coordination process with the PCP. This suggests that processes that change standard workflow or require an additional step may inhibit data sharing from the community setting. However, passive HIT strategies to collect and extract data can feasibly and effectively facilitate data sharing from a clinical to a nonclinical setting; thus, future iterations of this model should use passive, automatic processes in both settings.

Although WIC to PCP data sharing was less effective, the process was more efficient than in the reverse direction. The WIC to PCP data sharing process took 1 business day and was dependent on human resources. After the WIC nutritionist signed off of the WIC system, data were extracted that evening and sent to the research team in the clinical setting via a secure file transport portal and then integrated into the infant's EHR by a research team staff member the next morning. In contrast, after data were extracted from the EHR the morning after a WCV, data were sent via a secure file transport portal to a centralized team member at WIC, who uploaded the data to the WIC system, which refreshed at midnight via an automatic batch process. Thus, the process for PCP to WIC data sharing was 2 business days and was also human dependent. Due to staff availability in both the clinical research and central WIC settings, all data transfer steps were delayed by holidays and staff absences, planned and unplanned. Even though the data sharing process between PCPs and WIC was completed in 1 to 2 business days, future applications should aim to shorten this delay and automate the data transfer in real time. Addressing these limitations would accommodate participants who attend multiple visits within the same day or on consecutive days and reduce reliance on human resources, thus increasing the generalizability of the model to real-world settings with limited resources.

Care coordination was seldomly observed, in part due to the limitations of the data sharing processes, the wide variation in the attendance (frequency and pattern) of both WCVs and WIC visits, and the limited adoption of the PCP system to document RP care. Aside from logistical data sharing issues, enrollment of dyads after their first WCV or WIC visit, along with the sequence in which they attended visits throughout the study, limited opportunities for care coordination. However, when WIC nutritionists had the opportunity, documentation of RP care by the WIC nutritionists was high. Overall, dyads had 2 events with nutritionist documentation of RP care, which aligned with the 2 WIC visits attended. Almost all (193/197, 98.0%) of WIC visits with data shared to PCPs included documentation of this RP care. Nutritionists wrote a free-text comment to the PCP at a similarly high rate. In contrast, fewer participant records had evidence of PCP documentation of RP care, and PCPs only wrote a comment to WIC a total of 3 times. Overall, dyads had 1 event with PCP documentation of RP care despite attending 3 WCVs. Therefore, WIC nutritionists readily documented RP care and used the free-text comment feature, but adoption of this feature by PCPs was more variable.

Low adoption of the documentation features of the PCP system may be due to variations in PCP practice that limited exposure to the system. Infants were randomized at the individual level as opposed to the PCP or clinic level. Thus, a PCP provided well-child care to infants in the treatment group (with the PCP system) and control group (without the PCP system), as well as to infants not involved in the study (without the PCP system) throughout the 22-month study period, creating inconsistencies in workflow and exposure to the PCP system. Out of the 459 WCVs attended by intervention dyads, PCPs documented RP preventive education at 162 (35.3%) visits. Documentation of RP preventive education, however, was a proxy for PCP system use and did not capture if the PCP viewed the EHL assessment tool or data from WIC within the PCP system and documented education elsewhere, such as the WCV note. Adoption of interventional EHR components may be improved through randomization at the PCP level, longer exposure times to innovations, additional training and booster sessions, feedback on performance, and enhanced organizational factors, such as administrative and operational support [24,25].

High adoption of RP care by WIC nutritionists may reflect strong alignment with their focused program goals and requirements [1]. This is evidenced by the high frequency of documented RP care in participant WIC records. Documentation of RP care was facilitated by using standard WIC education codes and integrating study team–created codes into WIC's standard electronic system (QuickWIC). Further, at some WIC visits, nutritionists could use parent-reported EHL data available to inform care. However, parent completion of EHL and the required cadence for a PCP to WIC care coordination opportunity (ie, a WCV followed by a WIC visit) limited the availability of EHL data to the nutritionist to a single event per dyad. Even though EHL data were available at about half of WIC visits, nutritionists provided and documented EHL-related RP education at most visits with dyads. In comparison, PCPs comprehensively assess and address growth, development, and safety issues at WCVs but perceive WIC nutritionists as having more time to discuss important nutrition and feeding issues and predicted clear benefits in cross-sector integration and coordination [4]. Thus, sharing nutritionists' documentation of preventive counseling may provide opportunities for the PCP to coordinate care by allowing the brief reinforcement of messages or time to discuss new or other topics pertinent to the care of their patient.

The study demonstrated that HIT strategies can facilitate the collection, integration, and sharing of patient-reported data on parenting practices in 2 settings. Most parents routinely completed the EHL 2 or more times, and PCPs had access to parent-reported EHL data at about half of the visits, which was then shared with WIC nutritionists to view at more than half of the care coordination opportunities. Parent responses to the EHL were automatically integrated into the infant's electronic health record in the pediatric setting and into the study-specific WIC system to prompt PCPs and WIC nutritionists to provide tailored RP counseling. Integrating parent-reported data into health care professionals' workflow and electronic patient management system prior to a visit may lead to patient-centered care by highlighting timely concerns and streamlining patient assessment. However, electronic solutions to collect patient-reported information need to account for technology availability at both the patient and clinic levels so as to not exacerbate the digital divide seen between lower- and higher-income populations [26].

Reliance on human resources for data sharing impacted the reliability and efficiency of processes to transfer data between clinical and community settings to facilitate care coordination; however, the system developed for this study addressed stakeholder concerns related to security of data sharing across settings [4]. Importantly, given the imperative of protecting patient rights and the health system's responsibility to maintain privacy, patient consent to share a limited data set across settings is warranted [4,16,27]. Executing interinstitutional agreements between the community and clinical settings for limited data sharing with participant consent was a critical and substantial step in the development of data sharing processes and addressed stakeholder concerns. In addition, using in-person or over-the-phone staff recruitment to obtain participant consent using paper or electronic consent forms, as well as the use of a secure file transport portal, addressed privacy concerns related to the Health Insurance Portability and Accountability Act and data security [4]. Further innovations in HIT strategies are needed to more efficiently and effectively share limited patient data sets with aligned community and public health agencies to address limitations related to workflow, human resources, and timeliness. Within the clinical sector, HIT strategies have been used to facilitate efficient data exchange between providers, and technologies are emerging for data exchange between clinical and public health settings [28,29]. Pairing these HIT technologies with strategies for data integration, as described here, presents a rich opportunity for scaling cross-sector data sharing into practice in order to implement recommendations from integrated and coordinated care models, achieving collective impact and advancing population health objectives [9,15].

While a strength of the pragmatic study is the observation of real-life patterns of care, a limitation to testing care coordination was that few participants completed the expected 4 WCVs or 2 WIC visits in a 6-month observation period. Visit attendance, timing, and the sequence of visit types was not determined or controlled by the study team. Socioeconomically disadvantaged parents and infants experience many barriers to attending WIC appointments, including lack of transportation or childcare, conflicting activities, negative feelings about nutrition education, and frequent relocation [30]. Research in the prenatal period suggests that providing low-income additional supports, such as case managers or outreach and community health care workers [31], may enhance efforts to coordinate care between clinical and community settings by promoting timely visit attendance. Although WEE Baby Care was informed by a formative qualitative phase that captured the perceptions of stakeholders, including PCPs, WIC nutritionists, and parents [4], the perspectives of these stakeholders on the implementation of the intervention components were not captured, which limited our understanding of how PCPs and nutritionists integrated the intervention into their workflow. Additional training booster sessions and a longer intervention period may have improved adoption of the PCP and WIC systems through reminders and increased exposure. Further, the limitations of the WIC system and iterations of this model may be optimized, as WIC has implemented an updated, nationally standardized participant management system since the completion of this study, providing an opportunity to improve the technology as well as the potential for evaluation and spread. Recruiting dyads after the first WCV likely reduced the number of potential opportunities for data sharing and care coordination. Lastly, most of the participating low-income mothers were White, all were English speaking, and most had a high school diploma or higher. This was representative of the Geisinger region, but generalizability to the more diverse national WIC and low-income populations with lower educational attainment may be limited [32,33].

Advanced HIT strategies can share data across clinical and community settings, even in a socioeconomically disadvantaged area with shortages in health care services; however, improvements in the usability of key strategies are needed to facilitate care coordination and increase generalizability to other settings. In alignment with models calling for integration and care coordination across settings [9,15], this intervention employed a comprehensive set of advanced HIT strategies, including patient (parent) access to their infant’s EHR (patient portal), patient (parent) electronic completion of a risk assessment that becomes integrated into their infant’s EHR, secure data sharing mechanisms, the ability for PCPs and WIC nutritionists to communicate securely, system analytics to manage preventive care, and interoperability between clinical and community data systems [11,16]. Future research is needed to address process limitations affecting the reliability and effectiveness of data sharing and care coordination and the suboptimal use of health care services. Integrating clinical and community health care services through electronic data sharing with advanced HIT strategies could be an integral approach to providing coordinated, patient-centered health care to low-income, socioeconomically disadvantaged populations.

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Authors' Contributions

JSS and LBD led all aspects of the study concept. JSS and LBH developed the responsive parenting curriculum using materials developed by JSS and IMP. JSS, LBH, MM, SH, and SBH trained community nutritionists to deliver the intervention and monitored data collection. JM, SL, and SH recruited and verified participant eligibility. JSS, LBD, SH, IMP, and JFH developed the risk assessment tool and PCP system, and LBD, JM, and CS integrated the tool into clinical workflow. SB,GJ, and SS developed the WIC system and extracted data from WIC systems. LBD, AC, JM, SL, and SMRK developed the data integration and coordination tools. LBD, CS, and JFH trained pediatricians to deliver the intervention. SMRK, HAH, JSS, MM, and LBD developed the manual and process for data sharing and care coordination. SMRK and MM prepared the data for the coding process. SMRK and HAH coded the data. SMRK analyzed the data. All investigators made substantial contributions to portions of the study design and data collection. All authors have been involved in the critical revision of the manuscript and have given final approval to the submitted version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
CONSORT eHealth Checklist V 1.6.1.
[PDF File (Adobe PDF File), 1941 KB - pediatrics_v3i2e22121_app1.pdf]

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Abbreviations

EHL: Early Healthy Lifestyles
EHR: electronic health record
HIT: health information technology
INSIGHT: Intervention Nurses Start Infants Growing Healthy Trajectories
PCP: primary care provider
RP: responsive parenting
WCV: well-child visit
WEE Baby: Women, Infants, and Children Enhancements to Early Healthy Lifestyles for Baby
WIC: Special Supplemental Nutrition Program for Women, Infants, and Children

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Original Paper

Facebook Support Groups for Rare Pediatric Diseases: Quantitative Analysis

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Abstract

Background: Loneliness, social isolation, and feeling disconnected from society are commonly experienced by parents of children with rare diseases and are, among others, important reasons for special supportive care needs. Social networking platforms are increasingly used for health communication, information exchange, and support. In the field of rare pediatric diseases, qualitative studies have shown that Facebook online support groups are utilized by and beneficial for persons affected by rare pediatric diseases. Nonetheless, the extent of this usage has not been investigated.

Objective: This study aims to provide a comprehensive quantitative analysis of the extent of Facebook usage as a tool for rare pediatric disease support groups and to explore factors that influence a disease's representation on Facebook. These results potentially offer important insights for future public health initiatives and give direction to further research that can give much needed support to parents of children with rare diseases.

Methods: We determined rare pediatric diseases using the inventory of the online portal Orphanet. Facebook support groups were identified by searching 5 synonymous disease descriptions using the group category search bar. Disease- and group-describing parameters were statistically analyzed using standard descriptive statistical methods.

Results: 6398 Facebook support groups, representing 826 diseases (19.5% of all searched diseases), were found. 69% are private groups. Group type, size, activity (sum of posts, comments, and reactions calculated by Facebook), new memberships, and language varied largely between groups (member count: minimum 1, maximum 23,414; activity last 30 days: minimum 0, maximum 3606). The highest percentage of awareness and information groups was found for teratogenic diseases (18/68, 26%). The odds of finding a Facebook group increased according to the level of information available about the disease: known prevalence (odds ratio [OR] 3.98, 95% CI 3.39-4.66, $P<.001$), known disease type (OR 3.15, 95% CI 2.70-3.68, $P<.001$), and known inheritance mode (OR 2.06, 95% CI 1.68-2.52, $P<.001$) were all associated with higher odds of finding a Facebook group, as was dominant compared to nondominant inheritance (OR 2.05, 95% CI 1.74-3.42, $P<.001$). The number of groups per disease increased with higher prevalence.

Conclusions: Facebook is widely used as a tool for support groups for rare pediatric diseases and continues to be relevant. Two-thirds of the groups are private groups, indicating group participants' need for privacy, which should be further explored. The advantages and limitations of Facebook as a tool for support groups in the field of rare diseases should be further investigated as it will allow health professionals to use Facebook more meaningfully in their counseling and guidance of affected individuals and their family members.

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KEYWORDS

pediatric rare diseases; rare diseases; support group; online support; Facebook support group; social media; parent support; support group privacy; counseling

Introduction

Background

Many parents of children affected by rare diseases described caring for a child with a rare disease to be highly isolating—with loneliness, social isolation and feeling disconnected from society being mentioned as common problems [1]. Most parents had never come into contact with other parents of a child with a similar condition to that of their own child, and many were dissatisfied with the overall support that they had received for their child with a rare disease from any source [1]. Since rare diseases have per definition a very low prevalence (European definition of rare diseases: <1 per 2000) [2], affected individuals are often geographically dispersed. For many rare diseases there is a deficit of medical and scientific knowledge [2]. Rare diseases are often serious, chronic, and progressive, and persons affected by rare diseases are more psychologically, socially, economically, and culturally vulnerable [2]. Hence, parents of children with rare diseases have special supportive care needs [1].

Parent-to-parent peer support has been shown to have beneficial effects on parents of children with disabilities and children with additional needs [3]. Parents benefit from support groups most importantly by building social connections, gaining a sense of belonging [4,5], and developing a sense of control [5]. Support groups provide an environment for parent-to-parent support, which offers several benefits through improved social support. Participating parents can experience improved social connections [4], a heightened sense of control [5], higher family life congruence [6], and lower consequences of perceived stress [7].

Social networking platforms are increasingly used for health communication, information exchange, and support. Benefits of using social media for health-related online communication and community include connectedness, increased community support, and online support groups [8]. Several advantages of social media for online support have been identified, including international scope, unlimited number of participants, cost-effectiveness [9], and 24-hour availability [10]. However, there are limitations, such as questionable reliability [11], accuracy [9], quality [12], application to personal situations [11], and the possible misinterpretation [9] of information found online and on social media.

Founded in 2004, Facebook is one of the longest existing social networking platforms [13]. In the second quarter of 2019, Facebook reported 2.41 billion monthly active users [14]. Thus, chances are presumably high that another person affected by the same disorder also uses Facebook and would be eligible to form a support group. Facebook allows persons to connect independent of geographic location and offers options for both individual and group communication [13].

Prior Work

Parents of children with rare diseases are active internet users, search for information online [15], and use social media such as Facebook to communicate and link with others [12], showing that most parents are already familiar with Facebook and are, therefore, likely have the required social networking skills. Therefore, they could benefit by extending their Facebook usage to participation in support groups quite effortlessly.

To our knowledge, only little research exploring the specific topic of online support groups for rare pediatric diseases has been conducted so far. Content analyses of specific online and Facebook support groups have been performed (eg, on groups for cleft lip and palate, clubfoot, Hirschsprung disease, autism spectrum disorders, Dravet syndrome, and related epilepsy disorders [16-21]). Group members benefit from giving and receiving informational and emotional support and from connecting with others since meeting others with similar experiences has been shown to decrease isolation [10,16-19].

Research Rationale

Social support can provide several benefits for parents caring for children with chronic diseases, disabilities, additional needs, behavioral problems, and rare diseases [3-10,12,13,15,16,18,20]. Qualitative studies have shown that Facebook is utilized by and beneficial for persons affected by rare pediatric diseases. However, since these studies focused on specific conditions or groups, they failed to reflect the extent of support group usage and the overall representation of rare pediatric diseases on Facebook.

Our study therefore aimed to provide a comprehensive quantitative analysis of the extent of Facebook usage as a tool for rare pediatric disease support groups and at analyzing disease- and group-describing parameters to explore factors that influence a disease's representation on Facebook.

These results may offer important insights for future public health initiatives and give direction to further research which can improve much needed support of parents of children with rare diseases. The analysis of Facebook groups dedicated to rare pediatric diseases and their development over time, for example, shows how many groups and individuals could benefit from an optimization of support groups conditions on Facebook. Initiatives that aim to promote communication among affected families can use this analysis to learn about support group structures such as group sizes and privacy settings. Having built the foundation of a quantitative analysis, future research can, for example, focus on a more in-depth qualitative analysis of Facebook group. Furthermore, this study points to the need for health professionals who treat individuals with rare pediatric disorders or affected parents or caregivers or provide genetic counseling to get better acquainted with the topic of social media support groups in order to understand and promote the communication among parents or caregivers of children with rare disorders.

Methods

Data Collection

Rare diseases with childhood manifestation were identified using the inventory of the online portal for rare diseases and orphan drugs Orphanet). Orphanet uses the European definition of rare disease [22]. A rare pediatric disease is defined as a disease with onset before adulthood; thus, age of onset had to be defined as antenatal, conatal/neonatal, infancy, childhood or adolescent but not adult, older adult, or all ages. Data collected included disease name, 4 synonyms, ORPHAcode, Online Mendelian Inheritance in Man number, International Statistical Classification of Diseases Tenth Revision, disease prevalence, inheritance mode (autosomal or sex-linked, recessive or dominant, etc), age of onset and disease type (monogenic, deletion or alteration of a single gene; chromosomal, alteration in the number or structure of a chromosome; microdeletion, deletion of a small chromosomal segment; teratogenic disorder, result of exposure to teratogenic agent; mitochondrial; infectious disease; multigenic or multifactorial). Age of onset and disease type information was extracted from disease name or Orphanet disease description. Data were collected between January 1, 2019 and March 13, 2019.

Facebook support groups were identified by searching 5 synonymous disease names or descriptions using the Facebook group category search bar. The researcher used a Facebook account, newly created for this purpose, that contained only the researcher's name, picture, gender (female) and location (Cologne, Germany); but no activity (likes, shares, etc) expect for searching for aforementioned disease names. Groups were subcategorized according to their specific focus using the information available from the group title, the group category provided by Facebook's group categorization or the publicly available group description. Groups had to be clearly recognizable as support groups, groups to raise awareness and information, or support groups for individual patients. Groups that explicitly focused on research, fundraising and charity, medication sales, and disease-related pages were excluded from analysis (examples for categorization using group title *Disorder A fundraiser* was categorized as focus on fundraising and excluded from analysis, *Child B's journey with disorder C* was categorized as personal support group, *Disorder D: spread awareness* was categorized as awareness and information group). Data collected on Facebook included group type, name, language, privacy setting (public or private), foundation date, member count, and group insights. Group insights are provided by Facebook and displayed on each group information page, regardless of privacy status. They report activity (sum of posts, comments, and reactions calculated by Facebook) and new members during the past 30 days. Only groups with at least 1 member qualified. Foundation dates for groups on Facebook can be entered automatically or manually; manually entered foundation dates before Facebook launch in 2004 were excluded from analysis due to a lack of reliability of information. Data were collected between March 13, 2019 and March 31, 2019.

Data Analysis

Data were analyzed using standard descriptive statistical methods using SPSS statistics (version 26; IBM Corp). Normally distributed data are presented using mean and standard deviation, skewed distributions are presented using median and interquartile range, binary and categorical variables are presented using counts and percentages. Odds ratios (ORs) were calculated. The 1-sample Kolmogorov-Smirnov test was applied to test for normal distribution. Nonparametric tests (Spearman ρ correlation, independent sample Mann-Whitney *U* test) were applied. Binomial and chi-square tests were used to investigate binary and categorical variables.

This study has been reviewed by the Ethics Commission of the Medical Faculty of the University of Cologne (protocol 19-1027), and all research has been carried out within the scope of the approval.

Results

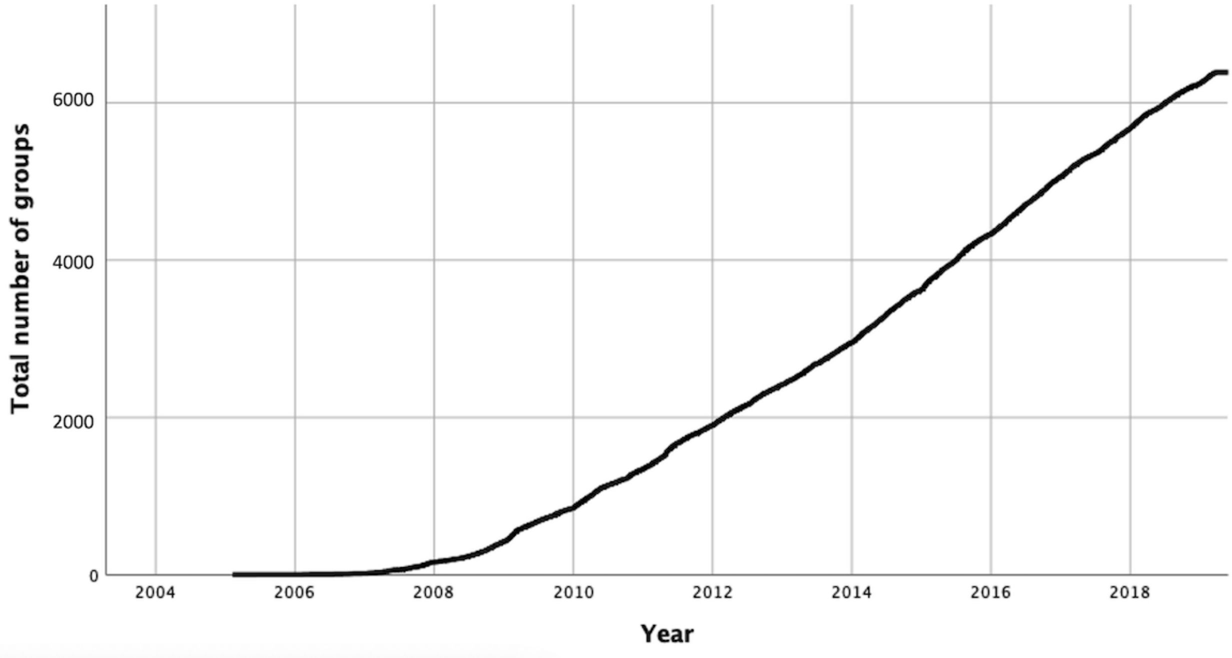
General

A total of 4246 rare disorders with onset before adulthood were identified using the Orphanet inventory, and 6398 support groups were found on Facebook. These groups represent 826 diseases, which amounts to 19.5% of all searched diseases.

The 10 diseases for which the most Facebook support groups were found are Down syndrome (145/6398, 2.3%), 22q11.2 deletion syndrome (117/6398, 1.8%), hypoplastic left heart syndrome (117/6398, 1.8%), Turner syndrome (97/6398, 1.5%), gastroschisis (95/6398, 1.5%), cleft lip and palate (93/6398, 1.5%), Ehlers-Danlos syndrome (93/6398, 1.5%), craniosynostosis (92/6398, 1.4%), microtia (90/6398, 1.4%), and retinoblastoma (89/6398, 1.4%). An alphabetic list of diseases on Facebook, including Online Mendelian Inheritance in Man number and the respective number of groups, is presented in Multimedia Appendix 1.

The total number of Facebook groups has continuously increased since 2008 (Figure 1). The number of newly created Facebook support groups shows fluctuation with an overall increase (Multimedia Appendix 2).

Figure 1. Development of the total number of Facebook support groups for pediatric rare diseases over time.



Disease-Describing Parameters

Of the 4246 diseases listed on Orphanet, 529 (12.9%) diseases show antenatal and 2815 (68.9%) show conatal/neonatal onset, 2167 (53.0%) start during infancy, 1074 (26.3%) during childhood, and 165 (4.0%) show adolescent onset. More than one age of onset may apply.

Table 1 depicts the distribution of disease type and prevalence among all identified diseases and diseases with at least 1 support group and the number and percentage of Facebook support groups per disease type and prevalence. 274/934 (29.3%) of the monogenic diseases, 51/145 (35.2%) of the chromosomal, 85/158 (53.8%) of the multigenic or multifactorial, and 4/22 (18.2%) of the teratogenic diseases found on Orphanet are represented on Facebook, and 376/2830 (13.3%) of the diseases with unknown disease type. The mean number of groups per disease increases with increasing prevalence (mean 2 for prevalence <1 per 1,000,000; mean 5 for prevalence 1-9 per 1,000,000; mean 14 for prevalence 1-9 per 100,000; mean 28 for prevalence 1-9 per 10,000).

Table 2 displays the number and percentage of diseases on Orphanet and diseases with at least one group following the different inheritance modes. More than one inheritance mode may apply.

ORs were calculated to compare the probability of a disease with known or unknown disease-describing parameters to be represented by at least one Facebook group: known prevalence (OR 3.98, 95% CI 3.39-4.66, *P*<.001), known disease type (OR 3.15, 95% CI 2.70-3.68, *P*<.001), and known inheritance mode (OR 2.06, 95% CI 1.68-2.52, *P*<.001) are all associated with higher odds of finding a Facebook group; as is dominant compared to nondominant inheritance (OR 2.05, 95% CI 1.74-3.42, *P*<.001).

Table 1. Diseases and Facebook support groups by prevalence and type of disease.

	Diseases found on Orphanet (n=4246), n (%)	Facebook support groups (n=6398), n (%)	Diseases with ≥1 group (n=826), n (%)
Prevalence			
<1 per 1,000,000	2516 (59.3)	620 (9.7)	253 (30.6)
1-9 per 1,000,000	150 (3.5)	452 (7.1)	85 (10.3)
1-9 per 100,000	188 (4.4)	1825 (28.5)	132 (16.0)
1-9 per 10,000	77 (1.8)	1251 (19.6)	44 (5.3)
1-9 per 1000	1 (<0.1)	0 (0.0)	0 (0.0)
Unknown	1314 (30.9)	2250 (35.2)	312 (37.8)
Disease type			
Monogenic	934 (22.0)	1623 (25.4)	274 (33.2)
Chromosomal	145 (3.4)	655 (10.2)	51 (6.2)
Mitochondrial	25 (0.6)	11 (0.2)	2 (0.4)
Infectious disease	2 (<0.1)	1 (<0.1)	1 (0.1)
Multigenic or multifactorial	158 (3.7)	988 (15.4)	85 (10.3)
Teratogenic disorder or infectious fetopathy	22 (0.5)	68 (1.1)	4 (0.5)
Micro-/contiguous gene deletion/duplication/triplication	130 (3.0)	290 (4.5)	33 (4.0)
Unclassified	2830 (66.7)	2762 (43.2)	376 (45.5)

Table 2. Pediatric rare diseases on Orphanet and diseases with at least one group that follow the different inheritance modes (more than one may apply).

Type[a]	Pediatric rare diseases on Orphanet that follow this inheritance mode, n (%)	Pediatric rare diseases with ≤1 group that follow this inheritance mode, n (%)
Autosomal recessive	1765 (55.6)	314 (38.0)
Autosomal dominant	971 (30.6)	279 (33.8)
X-linked recessive	306 (9.6)	75 (9.1)
X-linked dominant	70 (2.2)	25 (3.0)
Multigenic or multifactorial	74 (2.3)	31 (3.8)
Mitochondrial	15 (0.5)	1 (0.1)
Y-linked	1 (<0.01)	0 (0.0)
Inheritance not applicable	513 (16.2)	197 (23.8)

[a] More than one may apply.

Group-Describing Parameters

Group Type

The support groups are further divided into the following subcategories: general support groups (4385/6398, 68.5%), personal support groups (828/6398, 12.9%), support groups with focus on awareness and information (450/6398, 7.0%), not further specified groups (649/6398, 10.1%), groups for several diseases (86/6398, 1.3%). The following were not included: main focus on research (n=147), fundraising and charity (n=338), and medication sales (n=4). The highest percentage of awareness and information groups was found for teratogenic diseases (18/68, 26%).

Group Language

Disease names or synonyms were entered into the Facebook search bar in English. Groups were mostly English speaking (5721/6398, 89.4%), with a smaller number listing French (227/6398, 3.5%), Spanish (99/6398, 1.5%), German, Dutch, Portuguese, Swedish, Turkish, Polish, or Danish as the group language. In total, 38 different group languages were found (Multimedia Appendix 3).

Group Statistics

Group-describing parameters were not normally distributed. The sum of group members in all groups amounted to 1,784,435. Membership in more than one group was possible. The median number of members was 33 (IQR 183, Q1 5, Q3 188; for comparison: mean 278.91, SD 989.46). This varied between personal support groups (mean 87.50, IQR 238.75), general support groups (mean 44, IQR 217), and awareness and information groups (mean 15, IQR 105.25). The maximum group member count was 23,414 in a group for pediatric multiple sclerosis, the minimum was 1 member in 496 groups. Of these, 326 groups were the only Facebook support group for the respective disease. Of these groups, 268 (82.2%) were general support groups, 12 (3.7%) were personal support groups, 11 (3.4%) were awareness and information groups, 5 (1.5%) were groups for several diseases, and 30 (9.2%) were not further specified groups.

Throughout all groups, 84,966 new posts, comments and reactions were found (range 3606, minimum 0, maximum 3606; mean 0, IQR 3, Q1 0, Q3 3). In total, 4021 groups showed no group activity. 35,119 persons joined the identified Facebook support groups (range 1357, minimum 0, maximum 1357; mean 0, IQR 1, Q1 0, Q3 1).

Privacy Settings

When set to private, content, such as posts and pictures, is only accessible to members whose membership must be approved by a group administrator. Group title, group description, and group statistics including member count, new members last 30 days and activity last 30 days are always publicly available. Of the identified groups, 69% (4414/6398) are private, and 31% (1984/6398) are public. The sum of group members was 1,468,102 in private and 316,333 in public groups, with a maximum of 23,414 members in a private and 17,000 members in a public group. The median member count was higher in private (mean 46) than in public groups (mean 14). The median activity and new members in the 30 days prior to analysis was 0 for both private and public groups, with a sum of 78,023 activities in private and 6943 activities in public groups and a sum of 29,566 new members in private and 5553 new members in public groups. Performing an independent-sample Mann-Whitney *U* test showed that the distribution of the group-describing parameters differed slightly between the 2 privacy settings with higher member count, activities last 30 days, and new members last 30 days in private groups (member count: *U*=5,296,374, *z*=13.44, *P*<.001, effect size *r*=0.17; activities last 30 days: *U*=5,602,193, *z*=20.65, *P*<.001, effect size *r*=0.29; new members last 30 days: *U*=5,104,178, *z*=13.04, *P*<.001, effect size *r*=0.16).

Correlation Analyses of Group- and Disease-Describing Parameter

Correlation analyses showing relations between group- and disease-describing parameters are displayed in Table 3. The minimal age of onset correlates neither with the number of groups per disease nor with the group member count.

Table 3. Spearman correlations between disease- and group-describing parameters.

Interpretation, variables	ρ	*P* value
Significant strong positive correlation		
Recent group activity and number of new members	0.769	<.001
Significant moderate positive correlation		
Prevalence and number of groups per disease	0.530	<.001
Group member count and recent group activity	0.691	<.001
Group member count and new group members	0.628	<.001
Significant weak positive correlation		
Prevalence and group member count	0.101	<.001
Time that a group exists and member count	0.111	<.001
No significant correlation		
Time that a group exists and recent group activity	0.011	.39
Time that a group exists and number of new members	–0.002	.85
Disease’s minimal age of onset and number of groups per disease	–0.021	.55
Disease’s minimal age of onset and group member count	0.006	.62

Discussion

Principal Findings

Facebook is widely used as a tool for support groups for individuals affected by rare pediatric diseases. This study has shown that, for approximately every fifth rare pediatric disease, one can find an existing Facebook support group. Group type, size, activity, new memberships, privacy settings, and language vary largely between groups.

Within the first years after the launch of Facebook in 2004, only a few Facebook support groups for rare pediatric diseases were created. Starting 2008 and onward, the total number of Facebook groups has been following almost linear growth. Consequently, we expect the number of groups and the number of diseases represented on Facebook to further increase in the coming years.

Facebook Support Group Subtypes

Support group subcategories allow different group focus and benefits. Analyses of some general support groups have shown that group members give and receive informational and emotional support [19], exchange knowledge and advice [18], and benefit from the ability to connect with others via Facebook [16].

Personal support groups (about every eighth identified group) are dedicated to one specific child with a certain disorder. Information about this child's health is shared and discussed. This group format has similarities with a blog but offers more personal two-way communication and thereby opportunities for emotional support. These groups' creator and members may especially benefit from having a place to speak openly about the disease and feelings as well as from receiving emotional support, which are 2 main benefit categories identified by White and Dorman [9]. A possible explanation for why these groups show the highest median member count could be a different target group. While other support groups are usually joined by parents and other immediate family members [12,16-18,20], these groups are probably also joined by family friends, who receive health updates and offer comfort, but who do not have a child with a similar condition. It could be of interest to evaluate the impact of this method of receiving social support in the context of rare diseases, since such groups do not depend on disease prevalence and finding others with the same condition.

Almost every tenth identified support group also focuses specifically on creating awareness and providing information. This is in agreement with previous studies' findings: families of patients with rare disease often become involved in raising public awareness [10], and social media can increase rare disease awareness [23]. The highest percentage of awareness and information groups was found for teratogenic diseases. Many teratogenic diseases are preventable disorders and parents, caregiver, or patients might therefore utilize Facebook groups to spread awareness to prevent future cases of the same disease.

Insights Gained From Group Statistics

Facebook Group Accessibility

Even though we used English search terms, we found support groups in 38 different languages, indicating that Facebook support groups are a worldwide development. This supports that Facebook is a fitting tool for support groups since it is a globally accessible platform [13]. Facebook offers the possibility to easily and inexpensively share information 24 hours a day and time-zone independent [10,21]. Parents of children with rare diseases are active internet users and use social media such as Facebook [12,15]. Together with the aspect of internationality, Facebook is therefore accessible as a tool for support groups for many, if not most, caregivers for a child with a rare disease.

Group Members and Activity

Group sizes vary greatly. Group member count can be influenced by multiple factors, as we have shown for disease prevalence. Other factors may include group promotion among affected families and by health professionals.

Correlation analyses showed that groups with more group members also had slightly more recent group activity and new members. Support group participants could therefore benefit from joining a larger Facebook group, since it offers more active discussions and more individuals to connect with. Group activity and new member count showed a strong positive correlation, which indicates that new members start new conversations.

Many groups did not show any group activity. This could be either coincidental or indicate that these groups are inactive. Even if groups are formally inactive, there might still be private conversations between group members using Facebook Messenger or other personal messaging services, which we were not able to evaluate.

Looking for Others to Start a Support Group

Our analysis showed that 326 persons created a group for a specific disease, but at the time of study no one had joined their group, which means that they were unsuccessfully looking for someone to start a support group with. Possible reasons are that no one directly or indirectly affected by the same condition has turned to Facebook in order to look for a support group, or that no one is available for a support group on Facebook. Regarding the first explanation, it could be helpful to raise awareness of Facebook as a tool for rare pediatric disease support groups among parents and caregivers. A survey of caregivers of children with Autism Spectrum Disorders found that caregivers whose diagnosing clinician had referred them to a support group were more likely support group participants [20]. Therefore, health professionals ought to get better acquainted with the topic of social media support groups if they aim to promote the communication among parents and caregivers of children with rare disorders.

Facebook Support Group Privacy

A group's privacy setting limits access to the group. When set to private, membership must be validated by a group administrator before content such as posts and pictures can be accessed or created. Group description and group statistics are publicly available. Our analysis showed that two thirds of the groups were private, which is in agreement with a survey conducted among patients with newly described or rare genetic findings, of whom 60% were uncomfortable with sharing information in a public group [13].

Because of the need of a validation before joining a private group, we expected public groups to have higher member counts, but private groups' median member count resulted to be three times higher. More individuals appear to prefer joining private support groups, which indicates members' preference of a more private environment when sharing experiences related to their children's health.

Nevertheless, sharing information in a private Facebook group still means sharing information about a child online and oftentimes with (relative) strangers. Confidentiality and privacy issues are an important topic, since group participants are often unaware of risks of disclosing personal information [11]. Studies on mothers' habits of sharing private details on their children on Facebook regardless their children's health status have shown that mothers become increasingly aware of privacy issues on Facebook and try to find a balance between the need for privacy and the benefits of openness; some felt that some information was not appropriate to share [24,25]. This topic is particularly challenging since children cannot object to sharing information and pictures online, but might experience negative consequences later in life. Privacy issues therefore need to be investigated in the context of Facebook as a tool for rare pediatric disease support groups.

Factors That Influence a Disease's Representation on Facebook

The more individuals are affected by a disease, the more individuals potentially turn to Facebook to look for or create a support group. Many diseases with higher prevalence have several support groups, and these groups' descriptions often include geographic locations, eg different countries or states. Facebook group members have been shown to organize meetings for particular events [19], and Facebook groups organized according to members' locations could facilitate this.

The analysis of variables collected in this research showed that the odds of finding a Facebook group for a disease with known prevalence are almost four times higher compared to with unknown prevalence, for a disease with known inheritance two times higher than with unknown inheritance, and for a disease with known disease type more than three times higher than with unknown disease type. These findings suggest that the chances of finding a Facebook group increase with a higher level of understanding about the disease. New diseases are described regularly, but it takes time and resources to investigate newly described diseases, and for many rare diseases there is a subsequent deficit of medical and scientific knowledge [2]. It also takes time until more affected children have been diagnosed. This limited information and the factor of time influence the chance of finding a group on Facebook. Other factors may play a role as well. The impact of disease-specific mortality, for example, could be of great importance and might therefore be of interest for further investigation.

The odds of finding a Facebook support group for a disease with possible dominant inheritance are twice as high as for a disease without dominant inheritance. The risk of transmission in dominant diseases is 50%. Individuals affected by dominant diseases therefore encounter several challenges, such as reproductive decision making, feelings of guilt, and the need to communicate genetic risk with their children and family members [26]. These challenges can influence an individual's need for peer support, which may, in part, explain the higher probability of finding groups for dominant diseases.

Consequences for Treating Physicians and Other Health Care Professionals

This study indicates a need for health care professionals to become acquainted with social media as a tool for support groups, since it is already widely used. To allow informed decision making on whether to refer parents and caregivers of children with a rare disease to Facebook, more research about the strengths and limitations of Facebook as a tool for support groups is needed. If treating physicians decide to promote Facebook support groups, they can inform patients about the chances of finding a group, which is 1 in 5 overall but higher for monogenic, chromosomal, and multigenic or multifactorial diseases. Physicians with a focus on certain diseases can use our research to explore the extent of Facebook usage for groups for the respective disease. Furthermore, this study strengthens the importance of further research about rare diseases, since knowledge about a rare disease also influences the availability of support groups.

Study Strengths and Limitations

This study is a broad-scope analysis. All Orphanet-listed diseases which conform to the inclusion criteria were searched on Facebook using 5 synonymous disease descriptions. Nevertheless, it is impossible to know whether all existing support groups have been identified. Even though the Facebook search was conducted in English, groups in 38 different languages were identified. It is possible that not all existing non-English groups have been found, especially when disease names differ largely from the English disease name. Other groups regardless of group language may not at all use a disease description in their group title. Facebook search engine optimization may have influenced our search results using the researcher's information regarding location and gender. To minimize this effect, no other activities such as viewing, liking or sharing have been performed. Group activity and the number of new memberships could vary and since this was a cross-sectional study our data may not be representative. This could be investigated by repeating the study at another point in time. The limited information on Orphanet also limited our analysis. Disease type was evident for only a third of the diseases and information on prevalence was provided for only two-thirds of the diseases.

Conclusion

There has been a continuous rise in the number of support groups and diseases represented on Facebook since 2008. We expect that the relevance of Facebook as a tool for rare pediatric disease support groups will continue to increase. Group type, size, activity, new memberships, privacy settings, and language vary largely between groups. Support group subcategories allow different group focus. The odds of finding a Facebook group have been shown to increase according to the level of information available about the disease, and the number of groups increases with higher prevalence. Two-thirds of the groups are private groups, indicating the group participants' need for privacy, which should be further explored. More research is necessary to investigate the strengths and limitations of Facebook as a tool for support groups in the field of rare disease. This will allow health professionals to use Facebook more meaningfully in their counseling and guidance of affected individuals and their family members. It may also allow Facebook and other similar social media platforms to improve their toolkits and offerings for individuals affected by rare diseases.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Alphabetic list of diseases.
[DOC File , 711 KB - pediatrics_v3i2e21694_app1.doc]

Multimedia Appendix 2
The number of newly created Facebook support groups shows fluctuation with an overall increase.
[PNG File , 60 KB - pediatrics_v3i2e21694_app2.png]

Multimedia Appendix 3
Full list of Facebook support groups by language.
[DOC File , 51 KB - pediatrics_v3i2e21694_app3.doc]

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Original Paper

High School Students' Preferences and Design Recommendations for a Mobile Phone–Based Intervention to Improve Psychological Well-Being: Mixed Methods Study

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Abstract

Background: Young adults' mental health is characterized by relatively high rates of stress and anxiety and low levels of help-seeking behavior. Mobile health (mHealth) interventions could offer a cost-effective and readily available avenue to provide personalized support to young adults. More research needs to be directed at the development of mHealth interventions targeting youths specifically, as well as at determining how to reach young people and how to effectively intervene to improve psychological well-being.

Objective: The objective was to gather perceptions from high school students to inform the development of a prototype mHealth intervention aiming to promote psychological well-being.

Methods: A mixed methods design was used to (1) investigate high school students' perceptions about stress and its consequences in daily life, as well as their ability to cope with stress, and (2) explore their preferences and design recommendations for an mHealth intervention to improve psychological well-being. Students from two high schools in the southeast of Sweden were invited to take part in the study. Recruitment of high school students was completed over a 6-week period, between October 25 and December 7, 2018. Recruitment entailed inviting students to complete a stress test (ie, screening and feedback) on their mobile phones. After completing the stress test, all participants were invited to complete a follow-up questionnaire and take part in telephone interviews.

Results: A total of 149 high school students completed the stress test, of which 68 completed the questionnaire. There were 67 free-text comments distributed across the items. The majority of participants (55/68, 81%) stated that they coped with stress better or in the same way after engaging in the stress test, due to time management, dialogue with others, and self-refection. A total of 4 out of 68 participants (6%)—3 female students (75%) and 1 male student (25%)—took part in telephone interviews. Three main themes were identified from the interview data: perceptions about stress, design features, and intervention features.

Conclusions: Stress was described by the students as a condition caused by high demands set by oneself and the social environment that impacted their physical health, personal relationships, school performance, and emotional well-being. Participants claimed that mHealth interventions need to be clearly tailored to a young age group, be evidence based, and offer varied types of support, such as information about stress, exercises to help organize tasks, self-assessment, coping tools, and recommendations of other useful websites, literature, blogs, self-help books, or role models. Mobile phones seemed to be a feasible and acceptable platform for the delivery of an intervention.

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KEYWORDS

mental health; stress; high school students; intervention; mHealth

Introduction

Mental Health Among Youths and the Educational Sector as a Setting for Efforts

Mental health disorders account for about half of the disease burden among young adults in developed countries [1] and threaten health outcomes and academic performance [2-5]. Perceived high demands, peer relationships, academic pressure, lack of time management, parental pressure, school environment, recreational activities, low global self-esteem, and low social support have been identified as crucial factors that explain mental health problems in adolescents (eg, stress symptoms, sleeping problems, or worry and anxiety) [2,3].

Adolescents are in a vulnerable phase during which their future health behavior is being shaped. Behaviors developed during this period influence health in adulthood [1,6]. Most young people experiencing mental health problems do not access medical or professional services, leading to a risk to develop mental health disease later in life (eg, depression). Stigma and embarrassment about seeking help, confidentiality concerns, and poor mental health literacy are barriers to help-seeking [3,5,6].

The education sector can play an important role in mental health promotion among youths, especially when it comes to promoting stress management [7]. The schools' multidisciplinary teams provide good access to adolescents and school is a natural setting for mental health promotion [8]; as well, the context is appropriate because the stressors and demands on students partly concern school-related issues [9].

So-called psychosocial educational interventions, aiming to promote mental health, have been implemented in school settings. These interventions can be provided in meetings between the students, as individuals or in groups, and the teacher, mentor, or health professionals at the school health center [10,11]. These interventions include techniques to improve students' psychosocial health, relaxation training, stress management, problem solving, mindfulness, social adjustment, and emotional self-control. However, such interventions have demonstrated a limited effect on reducing symptoms of stress [12] and in preventing depression in the short term [11]. Also, psychosocial educational interventions are time-consuming, and school staff are not able to fully address these important issues due to high workloads and limited resources [3].

Mobile Health Interventions to Improve Psychological Well-Being

To address both the need to scale up interventions and to reach the groups that tend to be reluctant to seek help, and to offer efforts that require minimal resources and time, interest has increased to provide interventions via mobile phones. Such interventions fall under the umbrella term mobile health (mHealth) interventions, defined as a medical or public health practice that is supported by mobile devices [13]. mHealth interventions could offer a cost-effective and readily available avenue to provide personalized support to young adults. This intervention medium is especially suited for this group for several reasons. Mobile phone ownership and use are nearly universal. In addition, mobile phone interventions can be utilized at little cost and can be delivered at any time, to any location, with high fidelity. These interventions can also be utilized without the stigma of having to inform friends, family members, or school staff that one is seeking mental health support [14].

A recent meta-analysis showed that mHealth interventions can promote mental health, including stress management, among university students [15]. However, systematic reviews and meta-analyses [16-19] of the use of mobile apps and text messaging for mental health issues revealed several important limitations. These included lack of control or comparison groups, small sample sizes, an absence of theory-based interventions, and a high attrition rate. In addition, mHealth interventions are not sufficiently explained theoretically, not analyzed in enough detail to determine mechanism of change, and often focus on specific patient groups [20].

A fast-growing area of research is the documentation and critical analysis of the formative research process required in the development and refinement of effective mHealth interventions [21]. Systematic reviews underscore the urgent need for examining development processes for mHealth interventions [22] in order to fully understand how interventions have been developed to allow replication and adaptation of interventions across settings [23]. Previous research has pointed out that the most important factors during the design process is to be flexible and responsive to the input and feedback of the target audience: if they do not enjoy the program they may disengage [24]. More research needs to be directed at the development of mHealth interventions targeting youths specifically, as well as at determining how to reach young people and how to effectively intervene to improve psychological well-being.

Objectives

In this study, we aim to gather perceptions from high school students to inform the development of a prototype mHealth intervention aiming to promote psychological well-being.

Methods

Study Design

A mixed methods design was used to (1) investigate high school students' perceptions about stress and its consequences in daily life, as well as their ability to cope with stress, and (2) explore their preferences and design recommendations for an mHealth intervention to improve psychological well-being. Data collection was conducted through questionnaires and individual interviews. The study design followed recommended standards for mHealth development [24,25] and explored both preferences among the target audience regarding an mHealth intervention and general perceptions and experiences of stress.

Recruitment

Students from two high schools, aged between 15 and 19 years, in the southeast of Sweden were invited to take part in the study; the student population consisted of about 1000 students. The inclusion criteria for taking part in the study were as follows: (1) able to read and understand Swedish, (2) willing to complete a digital stress intervention (ie, screening and feedback), and

(3) own a mobile phone. The research project was advertised at the schools through printed media (ie, posters and leaflets), digital media (ie, student email and school website), and verbal information delivered by school staff in the classrooms.

Recruitment of high school students was completed over a 6-week period, between October 25 and December 7, 2018. Recruitment entailed inviting students to complete a stress test (ie, screening and feedback) on their mobile phones. The stress test was previously developed by our research group and consists of screening of stress symptomatology using the Perceived Stress Scale [26] and one item investigating sleep quality during the past month. The Perceived Stress Scale is a validated scale that measures global stress [26]. The stress test encompassed screening and feedback. The test gives feedback on stress levels and recommends stress-management strategies based on screening results. These strategies are all common evidence-based strategies, such as progressive muscle relaxation as well as cognitive behavioral therapy–based and mindfulness-based stress-reduction techniques.

Students registered their interest by sending a text message to a dedicated telephone number; they immediately received a confirmation message with information about the study and a link to the stress test. A total of 14 days after completing the stress test, all participants were invited, via text message, to complete a follow-up questionnaire and take part in telephone interviews.

Materials and Data Collection

The follow-up questionnaire aimed to investigate students' abilities to cope with stress, perceptions of the feedback given, and perceptions about support to cope with stress. The questionnaire included six items that had been generated for the purpose of this study (see Multimedia Appendix 1).

The aim of the interviews was to explore students' perceptions about stress and its consequences in daily life. Informants were also asked about their experiences of the stress test and perceptions about future mHealth interventions targeting stress among high school students. A semistructured interview guide was used [27]. The interview questions were framed around the following domains: (1) experiences of stress and its consequences on daily living, (2) use of the mobile phone for health informatics, and (3) user requirements and implementation aspects for an mHealth intervention to reduce stress. The interviewer was the first author of this manuscript (UM), a female researcher with a PhD degree and training and experience in qualitative methodology. The interviews lasted 45-60 minutes. Participants expressed their interest in taking part in the interview by leaving their names and phone numbers at the end of the questionnaire. The interviews were performed between February 17 and March 15, 2019.

Data Analysis

Questionnaire Data

Descriptive analysis [28] was used for the distribution of the responses to the questionnaire data. Free-text items were analyzed using manual content analysis [29]. First, all free-text data were read by the first author. Second, the free-text data were discussed among the authors, and comments that captured the main content of each specific question were selected. The free-text data were used to underline and illustrate the pattern of response to the fixed-response options.

Interview Data

Thematic analysis was used to analyze the professionally transcribed interview data [27]. The analyses followed a prescribed, sequential process: overall impressions were noted, data were reduced and coded into initial themes, we searched for patterns and interconnections, final themes were mapped and built, and conclusions were drawn [27]. The first author read the transcriptions to acquire a comprehensive understanding. The selected quotes were then compared between the authors, and agreement was reached on the quotes to be included. Statements that were not clearly in line with the purpose of this study were excluded. Themes were identified using an iterative process of reading and rereading the transcripts. Patterns were searched for, and coding into themes was initiated by the first author. Next, the themes were presented and discussed among all authors, and boundaries for themes were established jointly. Excerpts from the interview transcripts are presented to support and exemplify the categorization. The interviewees' fictitious names are given after their quotes, followed by gender and age.

Ethical Considerations

The study was approved by the Regional Ethical Committee in Linköping, Sweden (Dnr: 2018/269-31).

Results

Quantitative Data From the Stress Test

Overview

A total of 149 high school students—107 female and 42 male students—completed the stress test and were, therefore, invited to complete the questionnaire; 68 participants, all between 16 and 19 years old, completed the questionnaire. Overall, there were 67 free-text comments distributed across the items. Most comments related to perceived benefits of the intervention (n=18).

Ability to Manage Stress

The majority of the participants (55/68, 81%) stated that they coped with stress better or in the same way after engaging in the stress test, 2 participants (3%) stated that they handled stress worse after than before, and 11 (16%) stated that they did not know. Data showed that participants perceived stress differently and had learned how to prioritize their time:

> *I remember to think about the tips in certain situations I notice that I start to get stressed [about] and perhaps choose to say "No" to something I didn't have to do so that I get to do something else, which lowers my stress.*
>
> *I have noticed that I have started to see stress from a different perspective. If, for example, I am anxious about something and start stressing, I think, for example, that this will also pass.*

In contrast, data showed that learning about stress and raising participants' awareness could elevate stress levels:

> *I experience that I become more aware of stress and feel stressed about being stressed.*

A total of 12 free-text answers concerned the reasons why participants handled stress better now than before the intervention (eg, time management, dialogue with others, and self-refection); a few representative quotes are shown:

> *I believe it's probably because I try to plan my time better.*
>
> *That I think more about what makes me stressed. I find it easier to let go of things. I have tried to follow some of your advice. It has worked well and calmed me down; it has also helped me to minimize problems that I previously had blown up out of proportion, specifically because I feel life is easier when I stop and think about how I feel.*
>
> *I have talked with others and thought more about how I handle stress. I therefore think that I unconsciously handle stress in a better way.*

Perceptions About the Feedback Given

A total of 40 participants out of 68 (59%) found the feedback—tips, advice, and exercises—given to reduce stress to be *Good* or *Very good*. Among those who left free-text comments for this question, some stated that being screened for stress symptoms led to an awakening and increased awareness; they perceived not only that they were not as stressed as they thought, but also that they needed to manage stress differently:

> *It was like an "Aha" moment that I am too stressed, when I got a number put on it, because I have always thought that it was normal and that everybody else was just as stressed as me, but the number meant that I have started to think about it, and that I should learn how to handle my stress better.*
>
> *It made me realize that I do not stress as much as I think I do. That I can categorize my stress as necessary and unnecessary.*

However, only 14 participants out of 68 (21%) claimed that they had benefitted from the stress test. The participants underlined the need for tips and exercises to reduce stress in everyday life but pointed out the difficulty in following the given tips and asked for more tangible advice:

> *They were excellent tips, but [I] think the problem is actually putting those nine tips into practice.*
>
> *The feedback was good, but to have an effect perhaps we need more concrete tips.*

A total of 54 participants out of 68 (79%) answered *No* or *Don't know* to the question "Did you find the feedback usable?" Suggestions for improvements concerned the need to be able to revisit the feedback:

> *For me, the exercises have worked well; however, I thought it was a great shame that you couldn't go back and see the exercises and advice again after the test was finished. That is something that could definitely be improved.*
>
> *I did not have too much time to do them or test them.*

Furthermore, participants reported that the intervention content (ie, tips and advice) were redundant, well-known, and already available on the internet. Similarly, specific expert feedback was requested:

> *[I] didn't get any tips that I didn't already know about or used.*
>
> *These are comments that you can easily search for on the internet. [I] would have liked more tips from a professional who is an expert on all of this.*

Additional Support

Out of 68 participants, 30 (44%) indicated that they would recommend the test to a friend and 12 (18%) would not. A total of 14 (21%) participants contributed with suggestions for additional support. The following suggestions are examples given in the free-text comments:

1. "Planning and how to prioritize your work."
2. "Perhaps a video clip where you can listen to somebody who has had a problem and has solved it."
3. "I am less stressed after being physically active if it is a type of exercise I enjoy."
4. "Reminders on your mobile [phone] to destress."
5. "A hobby is very good, like painting, dancing, singing, etc."

Qualitative Data From the Interviews

Overview

A total of 4 participants out of 68 (6%)—3 female students (75%) and 1 male student (25%)—took part in telephone interviews. Three main themes were identified in the data: (1) perceptions of stress, (2) design features, and (3) intervention features (see Textbox 1).

Textbox 1. Three main themes and their subthemes identified from the thematic analysis.

Perceptions about stress:

- Experiences
- Consequences

Design features:

- Content characteristics
- Stress education
- Coping strategies

Reaching young adults:

- Duration and timing of support
- Enrollment
- Delivery

Perceptions About Stress

Perceptions about stress included both experiences and perceived consequences of stress.

Experiences

Participants described stress as a condition caused by high demands set by oneself, the school, and the social environment. High expectations of coping with stress in multiple settings emerged as a prominent trigger of actual stress and something that further contributed to a perceived imbalance in life:

> *But the type of stress I experience is very much linked to school, friends, and all the demands around this, the context, such as you must be slim, you must get good grades, you must exercise a lot, go to lots of parties, and, you know, all the pieces, that everything falls into place...I feel demands from my family that I have to behave in a certain way; I must be nice, help with the food, washing, and chores.* [Carl, 16 years, male]

> *School, schoolwork, trying to balance life with school, get good grades. It's not possible.* [Greta, 16 years, female]

Experiences of stress were also described as something positive, forcing one to get things done:

> *For me, stress is like both good and bad, when you know that there is something that must be handed in soon, and then you get stressed and so you do the things that have to be done; then it is a good thing and you actually do the things you have to.* [Carl, 16 years, male]

Consequences

Consequences of stress included feelings of frustration, being overwhelmed, and being unproductive when unable to prioritize. Furthermore, participants expressed that stress impacted their physical health, personal relationships, school performance, and emotional well-being. For example, students described health issues, such as migraine and sleep difficulties. Others explained that their school performance suffered due to the loss of concentration and not being able to prioritize. Regarding personal relationships, participants described difficulties remaining connected with friends:

> *When I have a lot to do and when I don't know what to prioritize, then I feel I get stressed. When I don't know what to start on first. And then it can end up with me not doing any of it; that can be the consequence of it...[I] often get quite frustrated when I don't know how to tackle it. So I have problems focusing on one thing.* [Maria, 17 years, female]

> *You can become so stressed that you just shut down, you can't manage any more, you're just too stressed, you can't even think...Sometimes I got so stressed that I got a migraine.* [Greta, 16 years, female]

> *I have had an awful lot of difficulty sleeping...You just carry the crap inside you and do not have the energy to keep up contacts with everybody.* [Carl, 16 years, male]

Design Features

Overview

Participants described what they thought would be important and valuable components of an mHealth intervention targeting mental health among high school students. Design features could be divided into three subthemes: content characteristics, stress education, and coping strategies.

Content Characteristics

Characteristics that the participants highlighted included that the content should be clearly tailored to a young age group, be evidence based, and offer varied types of support. For example, one participant stressed the importance of involving high school students in intervention development and creating a product that young people could relate to:

> *It's good that you keep in contact with, like, young people who, like, calls and talks with them, really have young people involved who keep track of this process, because I can promise you that if you want*

> *to have good contact with young people and reach them, having their opinions will really help.* [Greta, 16 years, female]

Furthermore, the value of interventions being evidence based was emphasized in the interviews; for instance, participants expressed that interventions and guidance grounded in research and best practice increase users' confidence to participate. Further, the need for recommended dedicated literature was also expressed as important to include in future interventions. References to other literature and support by an expert competent in the specific field of knowledge would help to screen the large volume of information available:

> *I listen a lot to things that are scientifically proven. I would think it was great to hear facts...you know, what is important and what you should listen to...it would be fantastic if somebody, an expert, who knows about these things could make recommendations.* [Carl, 16 years, male]

The importance of providing varied support to reach the many different personalities and needs was further highlighted by participants:

> *That it should be easily explained, and then that it should work for many people, as many as possible. That it isn't just text messages, but that perhaps, yes, but one could vary it a lot, I think that would be good.* [Maria, 17 years, female]

> *I think that you must be able to provide many different things in it, but that you have selected out that which is good.* [Susanne, 17 years, female]

When asked about the preferred style and an appropriate tone for the text messages, the clear response was that text should not be overly positive or optimistic:

> *Don't just be super positive and optimistic!...“Oh—keep fighting, after the rain comes the sun”; nobody wants to hear this, I can tell you...because if I get that sort of message, I just, like, delete that contact and block them, I don't want to hear that. Many, many, many of us are like that.* [Greta, 16 years, female]

Stress Education

Providing information about stress appeared to be fundamental. Participants stated that being provided with relevant information would help them to cope with stress and anxiety. Some described the need for access to information on how stress manifests and how to normalize stress. They also emphasized the importance of having a deeper understanding of their own reactions as a coping tool:

> *I think get knowledge about how it works, how it can affect you, at least for me I have got a good understanding and I have been able to manage it better. But then I've got help, that I now know how it works and what you can do about it.* [Maria, 17 years, female]

> *That there are different ways of looking at stress, so that you don't get stuck in your own bubble that “Oh, I have so much to do now,” because I think I get even more stressed from that now, because one should get, I don't know what it could be, but something that gets you to open up a little and understand a little more that “Yes, but OK, it isn't only me that is stressed.”* [Susanne, 17 years, female]

Following their need for information, participants suggested the inclusion of self-assessment in a future intervention to estimate their level of stress and to get to know their own stress triggers. Participants welcomed messages that included a link to a self-assessment survey and that gave regular feedback on their stress levels. They believe that such content could support self-reflection and make it easier to navigate when searching for the most useful support:

> *Exactly this with a test, that can also be good...just to be able to self-assess. Because then you reflect over yourself...it is important to know where you lie, that you get, so that you get the right type of relaxation and support.* [Carl, 16 years, male]

Participants stressed their need for recommendations of other useful websites, literature, blogs, self-help books, or role models. Some proposed that the intervention could have an accessible platform where they could choose various types of support from a range of resources with recommendations to relevant literature. The data showed that teenagers want quick results and consequently request shortcuts to useful support:

> *Honestly, I think you can send out recommendations to pages, recommendations to other things that you know are good, books...links to self-help books and other websites or blogs or such things. No, but you know, all teenagers want fast results so they can get on or something or be better at things quickly.* [Greta, 16 years, female]

Using people who had been in a similar situation and who had benefited from similar support as role models was suggested as a recommendation for other forms of support:

> *Yes, but perhaps it could present people who have been stressed but have perhaps gone through a similar program and feel less stressed. That you have a role model sort of. That it works so long as you don't stop. And that it isn't the same all the time, you have to have something new that isn't complicated.* [Carl, 16 years, male]

Coping Strategies

Time constraints and an inability to meet targets and organize time schedules were burning issues that triggered students' stress. All participants underlined the need for support to structure and organize tasks that had to be done at school and in daily living. They wanted advice and exercises to help organize tasks. Regarding the difficulties in structuring and prioritizing tasks, participants requested support in practicing how to take on one thing at a time. Furthermore, reminders or notifications to take time out and to do something else to relax were proposed:

> *Well I would like someone who says "Yes, but do this task now, then after you have done this task, then we move on to the next one." Like someone who, I know organizes it, or what one should say, very clearly with "Everything you are to do now is important, but you must start with one task so that you move forward," because I feel that I don't do that, I get stuck in what I have to do first...one needs to slow down a little so that you can test these exercises and see if you can remember how you should think and things like that.* [Maria, 17 years, female]

> *Definitely advice. So that you do something that breaks what you are stressed about and it doesn't spin out of control.* [Greta, 16 years, female]

> *Like, OK to be stressed now, but you can do something about it and then you can do this like, yes, but a little bit. Have a support, like.* [Maria, 17 years, female]

Some participants suggested recommendations for relaxation exercises and meditation. Others claimed that any kind of activity that decreases stress would be useful and proposed that a future intervention should encourage taking up a hobby or leisure activity:

> *What I really like is meditation, for relaxing, if you come home from school or have problems sleeping, putting on a meditation video and just listening to it, that is fantastic to do...important with advice on how to relax, anything...and just a reminder to take two seconds for yourself.* [Greta, 16 years, female]

> *Yes, but like get a hobby so you get away from it all for a little while, so to speak...but some people, they, like, want to go out and run, some want to sit and paint, some want to do yoga, find something.* [Carl, 16 years, male]

Reaching Young Adults

Overview

Participants described ways and preferences on how the target group could be reached and supported in their stress management. The data included suggestions on the methods for recruitment and delivery that would optimize a future mHealth intervention.

Duration and Timing of Support

The data showed that preferences regarding the length of a proposed intervention, the number of text messages sent per week, and the timing of messages differ from person to person:

> *It depends on the person. But a couple of months. I think, that for it to have an effect that it would have to be for more than a month...I wouldn't appreciate getting it every day. Because then I think I would feel a little overwhelmed. That isn't how you want it. Not continuously all the time. That would be too much. Then you'd just ignore it. But perhaps every third day.* [Carl, 16 years, male]

> *I think, like, every other day, because you don't want to get too much information about it or you wouldn't want it to feel forced, or I would at least...Then I think perhaps three weeks or thereabouts, three perhaps four.* [Maria, 17 years, female]

Participants indicated that simple messages, such as reminders sent a couple of times per week, with the aim of encouraging them to take a break, might be helpful in creating a sense of being supported by someone who cares about their situation:

> *But like, perhaps twice a week or something, not often but just a reminder every so often.* [Greta, 16 years, female]

The importance of being able to make one's own decision regarding the amount of support and duration of the intervention was stressed in the interviews:

> *So perhaps, say that you can have different types, if you can sign up say for a month or two months or whatever it is...Yeah, but I think that is best, because then it also gives you a feeling of having more control, which everybody wants to have, they want to be in control, because nobody wants [to] be completely out of control, without feeling "Yes, but I can choose whether I will have more or less."* [Greta, 16 years, female]

Concerning the timing of the delivery of the text messages, participants suggested delivery during the afternoon or evening:

> *And at the times perhaps when people are most stressed, I don't really know when that is, but perhaps some time in the afternoon when you get home from school and have to cram. Or in the evening, in the evening perhaps it would be good to get a reminder that you should go to bed early...not in lectures and such and on breaks when you have other things to do, I think, than listen to a program; you have to focus on what needs to be done.* [Susanne, 17 years, female]

Enrollment

The data showed that preferences regarding recruitment channels varied, indicating that high school students are a heterogeneous group and that employing multiple recruitment strategies is optimal. Strategies such as school staff advertising with posters in the assembly rooms and meeting halls, digital advertising through emails, and information in the classrooms were described as successful. Furthermore, social media was highlighted as a recruitment channel (eg, Instagram or Snapchat):

> *The teachers mean a lot, and things that they are behind, you listen to...If our teachers talk with us, we have mentoring every Monday, for example, then we sit and listen to what they are saying and they, that was when this test thing came up, the whole class did it. I think via the notice board in the school is best, because if we see it on Instagram, it is easy to just, once again, to just scroll down or ignore it. The school will always be a very good way to reach young people about things like this.* [Greta, 16 years, female]

> *That is a good way [via the school], but I think perhaps it could be good in some way to show oneself*

> *on social media. Instagram and Snapchat. But, as I said, the school is also a good way to go.* [Carl, 16 years, male]

Delivery

Participants found mobile phones to be a feasible and acceptable platform for the delivery of an intervention. Text messages, especially, seemed to be an appreciated method:

> *Well I thought it was a great idea that you get it directly to your mobile phone...I think it would be nice with SMS because otherwise it is easier to avoid doing anything about it, choosing not to go in and open the app and things.* [Maria, 17 years, female]

Discussion

Principal Results

This mixed methods study investigated how high school students perceive stress and their preferences regarding support for stress management. Our aim was to increase our knowledge in the area to develop an mHealth intervention aiming to promote psychological well-being among high school students. The questionnaire data showed that the stress test format (ie, screening and feedback) offered good stress-management support and increased the awareness about stress among participants. However, the data also showed that future interventions would benefit from more tangible advice and the ability for users to revisit advice and tips.

Three main themes were found in the interview data: perceptions about stress, design features, and intervention features. In general, the qualitative data showed that this population is a fairly heterogeneous group with varied support preferences and needs (eg, in regard to the timing and duration of an intervention). Also, the data showed that high demands from various life areas contribute to stress and that this group expects quick, easily accessible support and guidance on how to cope with stress. Finally, interview data suggested that mobile phones are useful as a platform for stress management but that specific features need to be considered for optimal reach.

Comparison With Prior Work

In this study, stress was described as a condition caused by high demands set by oneself and the social environment (eg, by the school and by people significant to the students). The most prominent cause of stress was high expectations of coping with stress in multiple settings. Previous research has stressed that young persons are actors in a social context in which they interact with, for example, peers, technology, social norms, and body ideals. Research points out that these cultural and social contexts need to be considered if we are to understand and approach mental health among young adults [30]. Furthermore, our data indicated that stress impacted on various life areas, such as physical health, personal relationships, school performance, and emotional well-being. Our findings highlighted the interest and curiosity among high school students regarding evidence-based information on how stress manifests and how to normalize stress among young adults. Following the need for information, some participants suggested the inclusion of self-assessment in a future intervention to estimate their level of stress. However, recent research problematizes the picture of youth mental health and points out the difficulty of measuring students' well-being in general, and stress in particular, based on symptom frequency.

A growing discussion in society concerns a need to distinguish in-depth problems from those of a more everyday nature. There is currently a major emphasis on diagnosis: a goal to provide a medical diagnosis and subsequently offer treatment [3,31]. For young people suffering from mental health problems but who are not "ill enough," there are no easy inroads to receiving scientifically reliable help for problems such as anxiety, sleeping difficulties, feeling down, and stress-related psychosomatic problems [3]. Thus, there is a need for future research to develop interventions targeting subclinical populations.

The findings from this study highlight the potential difficulty in accommodating a fairly heterogenous group with mHealth interventions. Although the challenge of tailoring intervention content and structure is relevant for any mHealth intervention, certain elements may be specific for the young adult age group. Our findings showed that high school students value specific features, such as evidence-based content that is aesthetically pleasing and easy to navigate. Furthermore, the findings showed that this group expects quick, easily accessible support, and they down-prioritize support that does not meet these criteria. Considering the vast number of mHealth interventions that are commercially available, this group could be challenging to reach if interventions are not specifically tailored to their age group and accommodating to these aspects [6,13,17,22,32].

High school students seemed to have a great amount of trust in the school staff, and they recommended recruitment via school health services. The results confirm the declaration made from the World Health Organization that the education sector can play an important role in health promotion among youths [13]. Furthermore, participants found mobile phones to be a feasible and acceptable platform for the delivery of an intervention. Text messages, especially, seemed to be an appreciated way to deliver the intervention, which is in line with the growing body of evidence supporting the significance of mHealth interventions to help people modify health behaviors [14].

Strengths and Limitations

This study has several limitations. First, a relatively short questionnaire was used to explore the views of the participants. Second, the interviews were few (n=4). As in all qualitative studies, the sample size was not based on power calculations, but rather on data saturation. When and how saturation is reached varies from study design to study design; hence, there is no one-size-fits-all method to reach data saturation. However, according to previous research using qualitative design [27], one way to think of data is in terms of rich and thick, rather than the size of the sample; that is, to differentiate between rich and thick data is to think of *rich* as high quality and *thick* as high quantity. One can have a lot of thick data that is not rich; conversely, one can have rich data but not a lot of it. In this study, we chose to conduct the research in a manner allowing us to reach data saturation by collecting rich (ie, high-quality) and thick (ie, high-quantity) data. We account for multiple sources of data and perspectives to ensure that the study results demonstrate validity through data saturation. Hence, strengths in this study were the use of a mixed methods design; analyses of the questionnaire data were enhanced when the quantitative data were viewed in relation to the patterns found in the qualitative interview data. Findings not captured or understood through numeric answers alone were exposed through the variations in data. Several steps have been taken to ensure the validity of the results. Regarding the questionnaire data, two authors read the free-text comments independently many times. The first author selected a variety of the most crucial free-text comments, and then the chosen free-text comments were presented and discussed with the other authors; comments that captured the main content of the specific question regarding the aim of the study were chosen. Free-text comments that were not agreed on by all authors were excluded. A similar procedure was taken when analyzing the interview data; two authors independently coded and analyzed the transcripts to improve the trustworthiness of the findings.

Conclusions

The adolescent period is characterized by rapid physical and psychological changes in the individual, together with increasing demands and influence from peers, school, and wider society. Including young people's own perspectives is of relevance to psychosocial health. Youths' experiences of feeling psychosocially well or not need to be heard and collected as basic information in scientific studies, including in the development of new interventions. This mixed methods study demonstrated the advantages of conducting a formative appraisal early in the process to guide the development of a prototype mHealth intervention aiming to promote psychological well-being. These findings will become imperative when designing a forthcoming mHealth intervention based on high school students' needs, perspectives, and recommendations.

The findings can contribute to a deepened understanding on how high school students experience stress and on important aspects of future stress-management support targeting this population. Indeed, the findings were helpful in learning about our intended target group, in assessing the health issue, in starting to identify the components of possible contents, in exploring the natural settings, and in how to reach young adults.

Acknowledgments

The authors thank the study participants for their participation in this project. This study is not supported by any grants or funding.

Conflicts of Interest

MB and PB own a private company (Alexit AB) that develops and distributes lifestyle interventions to be used in health care settings. Alexit AB had no part in funding or planning of this study.

Multimedia Appendix 1
Follow-up questionnaire.
[DOCX File , 12 KB - pediatrics_v3i2e17044_app1.docx]

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Abbreviations

mHealth: mobile health

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Viewpoint

Smart Indigenous Youth: The Smart Platform Policy Solution for Systems Integration to Address Indigenous Youth Mental Health

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Abstract

Indigenous youth mental health is an urgent public health issue, which cannot be addressed with a one-size-fits-all approach. The success of health policies in Indigenous communities is dependent on bottom-up, culturally appropriate, and strengths-based prevention strategies. In order to maximize the effectiveness of these strategies, they need to be embedded in replicable and contextually relevant mechanisms such as school curricula across multiple communities. Moreover, to engage youth in the twenty-first century, especially in rural and remote areas, it is imperative to leverage ubiquitous mobile tools that empower Indigenous youth and facilitate novel Two-Eyed Seeing solutions. Smart Indigenous Youth is a 5-year community trial, which aims to improve Indigenous youth mental health by embedding a culturally appropriate digital health initiative into school curricula in rural and remote Indigenous communities in Canada. This policy analysis explores the benefits of such upstream initiatives. More importantly, this article describes evidence-based strategies to overcome barriers to implementation through the integration of citizen science and community-based participatory research action.

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KEYWORDS

Indigenous youth; mental health; school policies; health policy; digital health interventions; mHealth; systems integration; land-based learning; physical activity

Indigenous Youth Mental Health: A Historical and Cultural Perspective

According to the World Health Organization, suicide is the second leading cause of mortality among individuals aged between 15 to 29 years [1]. Although suicide rates vary between and within countries across various subpopulations, evidence clearly indicates that youth—especially Indigenous youth in settler nations such as Australia, Canada, and the United States—have significantly higher rates of mental illness and suicide [2]. The United Nations identifies Indigenous Peoples as inheritors and practitioners of unique cultures and ways of relating to people and the environment, and state that they are arguably among the most disadvantaged and vulnerable groups of people in the world [3].

Indigenous Peoples' culture, language, subsistence, and ways of life have been adversely affected by a history of colonization and forced assimilation [4,5]. The resultant intergenerational trauma continues to influence the health status of Indigenous communities [6-8]. This history of dispossession is particularly challenging for Indigenous youth due to a loss of identity, which is reflected in significant health disparities, high suicide rates, and poverty [9].

Although Indigenous Peoples were historically a healthy population [10,11], inter-generational inequities have resulted in poor holistic health [12], which encapsulates physical, mental, social/emotional, and spiritual/cultural aspects. As Indigenous Knowledge emphasizes that these varied aspects of holistic health are interdependent and interrelated, an imbalance across the spectrum of holistic health is detrimental to Indigenous Peoples [11,13].

With respect to youth mental health challenges, although there are indications of significant differences in prevalence across Indigenous communities [14], a common pattern is the dearth of Indigenous Knowledge use in facilitating youth mental health. This is disconcerting because evidence indicates that Indigenous Peoples possess the knowledge to enable culturally rich environments for youth to thrive. More importantly, while Indigenous Knowledge can be transferred across communities to enable Indigenous Ways of Knowing so that struggling communities can benefit from the success of thriving communities, this approach is rarely incorporated into policy or program decisions [14].

The push for preventive mental health policies and programs across settler nations is commendable, yet there is a risk of taking a one-size-fits-all approach in scalable interventions that are focused on top-down implementation rather than bottom-up, culturally appropriate, and strengths-based prevention strategies [15]. A potential key to the success of these strategies is the transfer of Indigenous Knowledge across communities by ensuring cultural connectedness that is specific to each community [14].

Culture incorporates spirituality, identity (individual, family, community, and nation), and traditions [16]. Strong cultural identity and cultural connectedness have been associated with better health, higher self-esteem, positive mental health, and lower rates of binge drinking [16-21]. Cultural connectedness can also act as a coping mechanism to deal with historical trauma, thus increasing personal and community health [21].

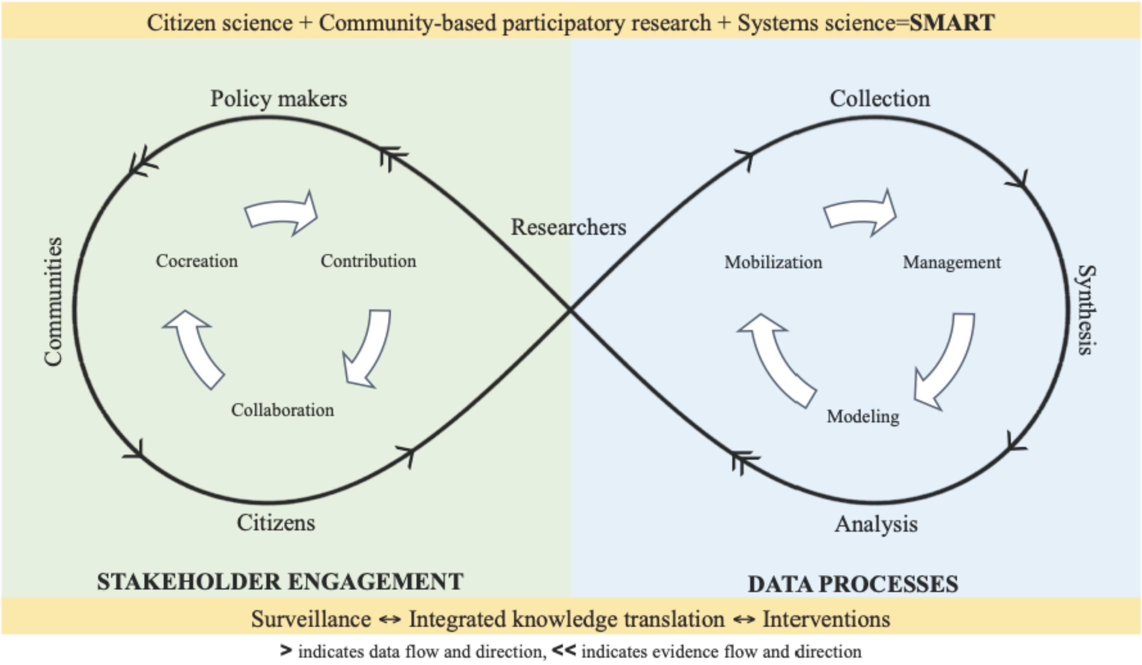
With such strong evidence of culture playing a role in holistic health, there is a need to normalize culturally appropriate policies and programs to facilitate Indigenous youth mental health [22]. However, these approaches need to be embedded in replicable and contextually appropriate mechanisms such as school curricula across multiple communities to ensure the exchange of Indigenous Knowledge [14]. In order to engage the youth of the twenty-first century, especially in rural and remote Indigenous communities, it is also imperative to leverage ubiquitous mobile tools for digital health interventions to not only address access gaps, but also to empower Indigenous youth. This approach will facilitate innovative Two-Eyed Seeing solutions [23-25], which incorporate Western digital epidemiological methods with Indigenous Knowledge.

Smart Indigenous Youth: An Innovative Systems Integration Policy Solution

Smart Indigenous Youth embeds a land-based, culturally appropriate, active living digital health initiative into school curricula to promote mental health, minimize substance abuse, and prevent suicide among Indigenous youth (13-18 years old) in rural and remote areas of the Canadian province of Saskatchewan. In implementing Smart Indigenous Youth, we are integrating services supported by the Saskatchewan ministries of health, education, and sport, thus enabling a policy of systems integration. The initiative uses the Smart Platform [26,27], which is the first citizen science and digital epidemiological platform for ethical population health surveillance, integrated knowledge translation, and policy and real-time interventions.

Citizen science approaches range from contributory and collaborative methods (data collection and analysis) to cocreation of knowledge (conceptualization and knowledge translation), where all participants contribute as citizen scientists [23,27,28]. The Smart Platform is informed by an evidence-based framework that integrates citizen science, community-based participatory research, and systems science through digital tools to conduct population health research in the digital age—the Smart Framework (Figure 1) [23]. In implementing Smart Indigenous Youth, our team combines the Smart Framework with Traditional Indigenous Knowledge to ensure Two-Eyed Seeing for participatory action research [24,25]. This approach aligns with the concept of citizen science, where knowledge is cocreated with Indigenous Peoples as equal partners.

Figure 1. The Smart Framework.



Smart Indigenous Youth is a mixed-methods 5-year longitudinal active living community trial. The initial pilot was conducted in 2019 with 2 schools located within 2 rural First Nations reserves in Saskatchewan, Canada. In Canada, Indigenous Peoples consist of 3 groups: First Nations, Inuit, and Métis. The discriminatory categorization of Indigenous Peoples in Canada is a complex subject, which is beyond the scope of this policy analysis but could be perused in Smylie and Allan's report, "First Peoples, Second Class Treatment" [29].

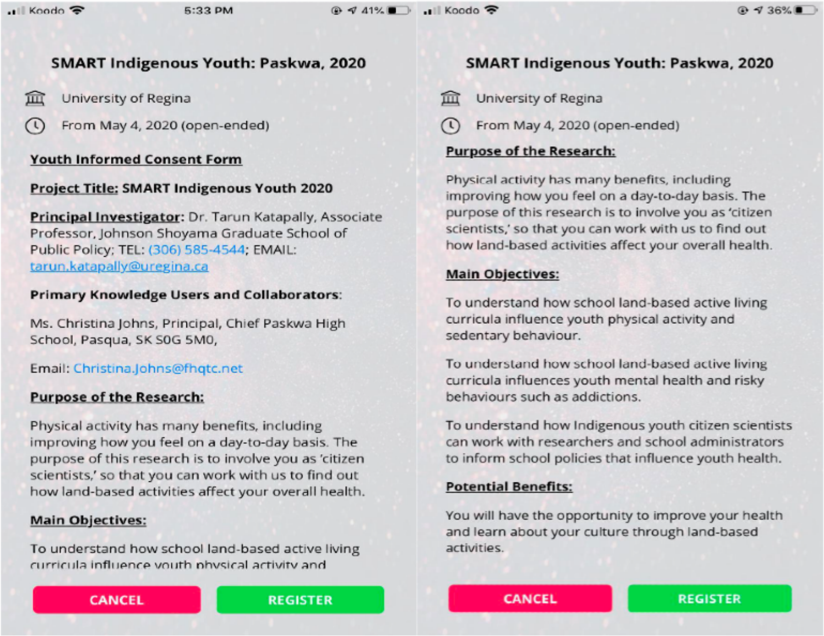
A reserve is a piece of land allotted to First Nations bands under the Indian Act, where First Nations band members have the right to live, and band administrative and political structures are located. First Nations do not have title to reserve lands, which are held in trust for bands by the British Crown [30]. Reserves often consist of less valuable land and are located outside the traditional territories of First Nations. Traditional hunting and gathering, which was the livelihood of many First Nations Peoples, was severely affected by the relocation away from First Nations' traditional territories, which were usually rich in natural resources [31].

Before the implementation of the Smart Indigenous Youth initiative, our team built strong partnerships with the communities based on equity, respect, and co-ownership. This partnership articulates not only study coconceptualization and cocreation of knowledge, but also co-ownership of data and integrated knowledge translation. Ethics approval was obtained from the Research Ethics Boards of Universities of Regina and Saskatchewan through a synchronized review protocol (REB # 2017-29).

In 2019, the study pilot year, 76 Indigenous youth citizen scientists (n=50 from School 1, n=20 from School 2), aged between 13-18 years, engaged with us in real time via a custom-built smartphone app using their own smartphones during their winter school term (ie, the intervention period). At baseline, Indigenous youth citizen scientists provided quantitative data using a combination of traditional validated measures and ecological momentary assessments via their smartphones. This quantitative data captured their physical activity, sedentary behavior, mental health, and substance abuse, among other behaviors and outcomes.

Before any engagement and data collection, Indigenous youth provided informed consent via the app (Figure 2) and had the option to drop out of the study (Figure 3) or pause data collection (Figure 4) at any time they wished. From the original cohort of 76 youth, 34 youth citizen scientists (n=16 from School 1, n=18 from School 2) became part of the Youth Citizen Scientist Council, which participated in baseline focus groups. Moreover, 2 school principals became educator citizen scientists to provide data on school policies and programs using the same custom-built smartphone app.

Figure 2. Citizen scientist informed consent via the smartphone app.



SMART Indigenous Youth: Paskwa, 2020

University of Regina

From May 4, 2020 (open-ended)

Youth Informed Consent Form

Project Title: SMART Indigenous Youth 2020

Principal Investigator: Dr. Tarun Katapally, Associate Professor, Johnson Shoyama Graduate School of Public Policy; TEL: (306) 585-4544; EMAIL: tarun.katapally@uregina.ca

Primary Knowledge Users and Collaborators:

Ms. Christina Johns, Principal, Chief Paskwa High School, Pasqua, SK S0G 5M0,

Email: Christina.Johns@fhqtc.net

Purpose of the Research:

Physical activity has many benefits, including improving how you feel on a day-to-day basis. The purpose of this research is to involve you as 'citizen scientists,' so that you can work with us to find out how land-based activities affect your overall health.

Main Objectives:

To understand how school land-based active living curricula influence youth physical activity and

SMART Indigenous Youth: Paskwa, 2020

University of Regina

From May 4, 2020 (open-ended)

Purpose of the Research:

Physical activity has many benefits, including improving how you feel on a day-to-day basis. The purpose of this research is to involve you as 'citizen scientists,' so that you can work with us to find out how land-based activities affect your overall health.

Main Objectives:

To understand how school land-based active living curricula influence youth physical activity and sedentary behaviour.

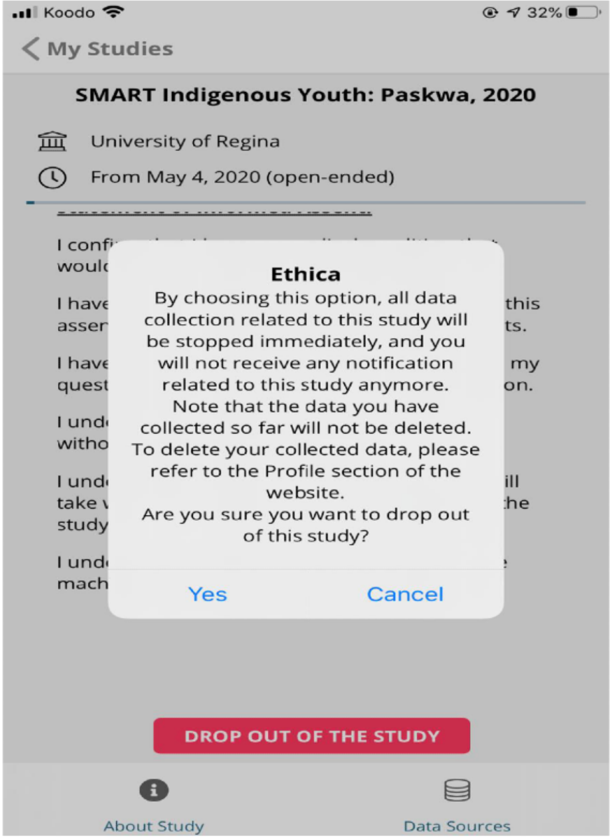
To understand how school land-based active living curricula influences youth mental health and risky behaviours such as addictions.

To understand how Indigenous youth citizen scientists can work with researchers and school administrators to inform school policies that influence youth health.

Potential Benefits:

You will have the opportunity to improve your health and learn about your culture through land-based activities.

Figure 3. Study dropout option for citizen scientists.



SMART Indigenous Youth: Paskwa, 2020

University of Regina

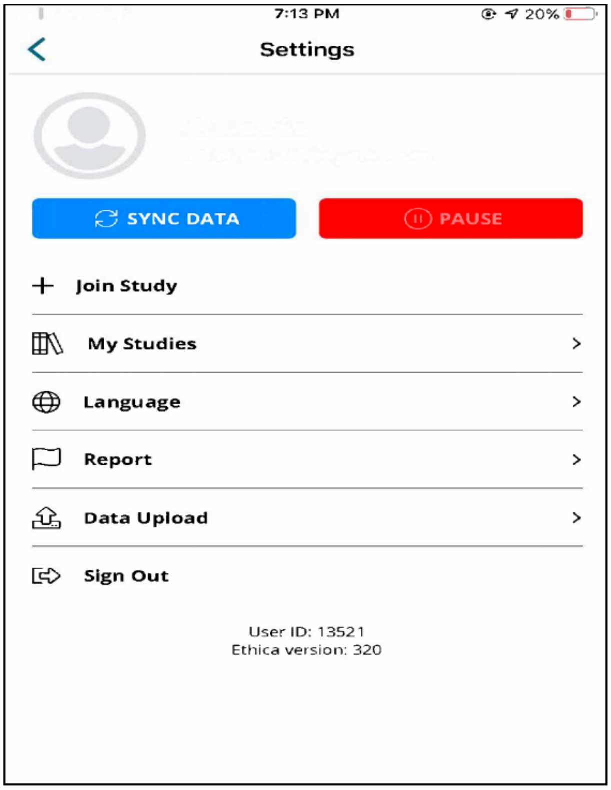
From May 4, 2020 (open-ended)

Ethica

By choosing this option, all data collection related to this study will be stopped immediately, and you will not receive any notification related to this study anymore. Note that the data you have collected so far will not be deleted. To delete your collected data, please refer to the Profile section of the website.

Are you sure you want to drop out of this study?

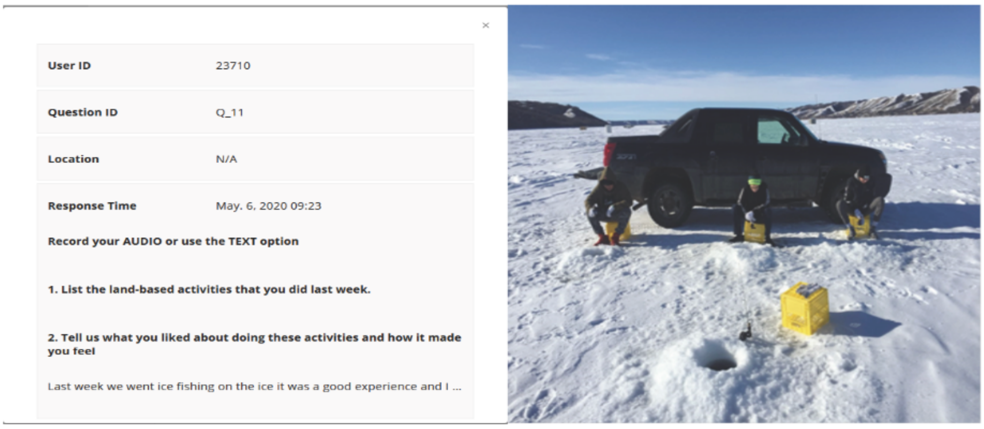
Figure 4. Data pause option for citizen scientists.



User ID: 13521
Ethica version: 320

Thereafter, each school initiated separate 4-month (winter term) land-based active living programs that were specific to their culture, community, geography, and language (Cree and Soto). Land-based activities included traditional hunting, trapping, fishing, foraging, and plant identification, as well as recreational activities such as canoeing and hiking. After the winter term, follow-up focus groups were conducted with the Youth Citizen Scientist Council to evaluate the impact of the culturally appropriate land-based intervention. Moreover, during the 4-month intervention period, youth and educator citizen scientists engaged with researchers in real time using their smartphones to capture the perception and impact of land-based activities through time and user-triggered ecological momentary assessments (Figure 5).

Figure 5. Ecological momentary assessments enabling citizen reporting of culturally appropriate land-based activities.



User ID 23710
Question ID Q_11
Location N/A
Response Time May. 6, 2020 09:23

Record your AUDIO or use the TEXT option

1. List the land-based activities that you did last week.

2. Tell us what you liked about doing these activities and how it made you feel

Last week we went ice fishing on the ice it was a good experience and I ...

The initial findings from the analysis of mixed-methods data depict the overarching importance of culture, identity, history, and language, where land-based activities such as canoeing and setting traps played a role in improved youth mental health by providing youth a sense of purpose and identity. More importantly, Indigenous youth citizen scientists continue to play a critical part in integrated knowledge translation, as evidenced by our first round of knowledge mobilization, which provides a voice to Indigenous youth to contribute to the systems integration of the Smart Platform through digital engagement [32].

Benefits

Digital Health Interventions Enabling Systems Integration

The primary significance of the Smart Indigenous Youth initiative is systems integration (health, education, and sport) to develop health policies that are embedded into school curricula. Current evidence clearly indicates that although Indigenous youth in rural and remote regions across the globe are more susceptible to poor mental health outcomes, existing healthcare policies do not meet the needs of Indigenous youth [33,34]. The World Health Organization's Mental Health Action Plan 2013–2020 has a global target of a 10% reduction in suicides by 2020 by strengthening information systems [35]. It is not evident if we are closer to achieving this goal, but addressing youth mental health—especially challenges faced by Indigenous youth—should be part of long-term plans to improve global mental health.

A recent systematic review that evaluated the evidence of intersectoral interventions addressing Indigenous child and youth mental health not only recommended novel responses, but also indicated that the success of these interventions will depend on the collaboration, cultural sensitivity, and empowerment of participants [36]. Moreover, this review recommends further research on the impact on social determinants of health, the extent of participant engagement, and Indigenous voices.

Smart Indigenous Youth enables an intersectoral intervention by bringing together health, education, and sports-related policies through a culturally sensitive and land-based initiative that empowers Indigenous youth by providing them a voice. The key to the success of Smart Indigenous Youth's systems integration is the innovation of combining citizen science, community-based participatory research, and systems science through ubiquitous devices [23]. This integration facilitates digital health interventions for mental health equity among Indigenous youth. The participatory approach of Smart Indigenous Youth creates opportunities for scalable and replicable digital health interventions since it is based on the implementation of a global digital citizen science policy [37].

Holistic Health Benefits, Including Mental Health

Evidence is well-established that active living not only combats the effects of chronic diseases but also interconnects and balances the 4 aspects of holistic health, recognized as physical, mental, social/emotional, and spiritual/cultural, within Indigenous worldviews [38-40]. The existing mainstream structure of active living access in schools, where the focus is on competitive sports, leads to cultures of privilege, exclusivity, and isolation [39]. Such an approach to physical activity goes against established evidence that the emphasis of healthy, active living should go beyond participation in structured competitive sports [41].

Land-based active living initiatives are a conduit for connecting with cultural roots to counter the impact of historical colonization and for providing holistic healing mechanisms that facilitate Indigenous youth mental health [42]. Smart Indigenous Youth is the first initiative to utilize digital citizen science approaches to focus on culture and local Indigenous Knowledge in understanding the pathways through which land-based active living influences mental health. This initiative builds on previous research on Indigenous youth engagement with nature using photovoice and the Two-Eyed Seeing framework [43]. This nature-based research concluded that urban Indigenous youth found nature to be a calming place that enables them to cope with stress, anger, and fear, among other difficulties they face in everyday life.

Indigenous Youth Empowerment

Given the burden of historical trauma and continued marginalization that affects the well-being of Indigenous youth, Smart Indigenous Youth uses a strengths-based approach that shifts the perceived deficits away from the individual. Instead, the emphasis is on placing health problems in the appropriate context, such as the oppression of residential schools [44]. Becoming citizen scientists allows youth to focus on their strengths and build resilience to face challenges related to anxiety, depression, and even substance abuse. Smart Indigenous Youth expands this approach to rural and remote Indigenous youth who are currently underserved by existing healthcare systems [33,34]. In implementing Smart Indigenous Youth, we focus on holistic health benefits by empowering youth with digital tools, where they engage with researchers in real time.

A key component of facilitating empowerment is building capacity among Indigenous youth for integrated knowledge translation. Smart Indigenous Youth is based on the Smart Framework's integrated knowledge translation approach [23], which is strengthened by the Youth Citizen Scientist Council with representation from varied genders and socioeconomic groups. The evidence that is generated by this initiative is disseminated and translated in collaboration with the Youth Citizen Scientist Council, which provides a voice to Indigenous youth as depicted by our first round of knowledge mobilization [32].

Barriers to Implementation

The primary barriers to implementation of Smart Indigenous Youth include systemic issues such as school principal employment term limits, participant burden in terms of citizen scientist compliance, and technological constraints such as internet inequity.

Systemic Issues: Limits on School Leadership

In implementing this complex digital health initiative into school curricula, a key component is relationship building with school leadership. The school principals who co-lead this initiative are the community champions that drive the implementation along with the research lead. Without the establishment of a strong partnership with school principals, this initiative would not succeed. Moreover, building partnerships takes time, as the research lead needs to understand not only the challenges of Indigenous youth but also the historical, cultural, and socioeconomic context of the communities within which the schools exist.

The school principals ensure the successful implementation of the initiative by coordinating and integrating the initiative into existing school protocols. Thus, the current term limit of 1 year for school principals places a major barrier in implementation as there is a risk that existing school principals, with whom strong partnerships have been established, will be replaced with new leadership. Such a scenario will not only result in the loss of valuable partnerships but also slow down the continuity of implementation, as new relationships would have to be established with new principals.

Participant Burden: The Role of Citizen Scientists

Indigenous youth and educators in each participating school participate and contribute to the Smart Indigenous Youth initiative as citizen scientists. This can cause substantial participant burden, as the expectation of citizen scientists is to play an equitable role in the initiative. This scenario varies significantly from studies where the expectation from participants ends with the provision of data. Citizen scientists in the Smart Indigenous Youth initiative have to longitudinally engage with the research team to provide not only quantitative and qualitative data using their own mobile devices but also participate in consultations for implementation and knowledge translation. As such, participation requires considerable commitment and investment in terms of time and energy, and could thus lead to considerable participant burden.

Technological Constraints: Internet Inequity

The most significant barrier to digital health interventions, especially in rural and remote communities, is internet inequity. Internet inequity is defined as differential internet access based on wealth, location (urban, rural, or remote), gender, age, or ethnicity [23]. In our experience of working with rural and remote schools, our team has observed that although more than 90% of youth and educators own smartphones, access to Wi-Fi or cellular data plans varies widely between communities, and it is not always the case that remote communities have lower access. For example, the most remote school in our initiative provided better Wi-Fi access to their students as part of their school curricula. However, it cannot be assumed that students from more remote schools will have better access to Wi-Fi outside of school hours, especially in their homes. That is, individual socioeconomic status plays a major role in internet access outside of school hours.

Evidence-Based Strategies to Address Barriers

Integrating Citizen Science and Community-Based Participatory Research Action

To circumvent school principal term limits and minimize citizen scientist burden, we employ the integration of citizen science and community-based participatory research action. As citizen science can range from contributory (data collection) and collaborative approaches (analysis and interpretation of data) to cocreation of knowledge (conceptualizing research and translating knowledge) [23,27,28], it has a natural overlap with community-based participatory research action. Moreover, as community-based participatory research action is entrenched in human rights and social justice, it can be applied to promote local policy change by bringing together community needs, scientific evidence, and political power [45,46]. By taking this approach, and by turning the challenge of school principals' 1-year terms into an opportunity, we are working to potentially expand Smart Indigenous Youth to new schools to which principals may be transferred. Thus far, we have been able to successfully expand the initiative to 1 more rural school in 2020 due to the transfer of a school principal from the 2019 pilot.

To tackle citizen scientist burden, we established the Youth Citizen Scientist Council, which provides a voice to Indigenous youth to inform and influence school policies that are relevant to their holistic health [32]. This has maximized compliance as we have structured citizen science endeavors using community-based participatory research action principles, where citizens co-design studies and cocreate knowledge with researchers by contributing to all aspects of the research process. The integration of citizen science and community-based participatory research action is being catalyzed by the ubiquitous presence of smartphones that we are leveraging to overcome traditional constraints in terms of participant recruitment and retention, data collection and analysis, interventions, and knowledge translation [27].

Indigenization of Academia

In implementing initiatives such as Smart Indigenous Youth, strategic support from academic institutions, where the research is based, is critical for the ultimate success of these collaborative projects that are intensive in terms of human resources, time, and logistics. For instance, engaging Indigenous youth and educator citizen scientists requires recognizing their contribution with culturally appropriate incentives. This research is being conducted with a federally funded grant that earmarks participant incentives in the budget; however, there was a need to indigenize the financial processes to ensure the timely delivery of incentives.

For instance, our team had to influence purchasing and reimbursement processes so that citizen scientists received incentives before they participated in the initiative. Similarly, we also had to influence financial regulations to ensure that the relevance of incentivizing Indigenous citizen scientists is not questioned at the institutional level. Ultimately, the success of this difficult bureaucratic task depended on academic leadership in engaging citizens, communities, and institutional management to address population health issues that are of concern to citizens, communities, policymakers, and researchers.

Local Solutions to Tackle Internet Inequity

As part of the Smart Indigenous Youth initiative, we are engaging with policymakers, communities, schools, and citizens to develop bottom-up approaches for improving internet access to Indigenous youth. We are addressing this complex issue at 2 levels: (1) by engaging schools to provide participating youth access to school Wi-Fi before, during (class breaks), and after school hours; (2) by budgeting funds to provide mobile data plans to the most disadvantaged youth. In our experience, individual data plans are better suited than mobile Wi-Fi hotspots because they provide continuous data access to enable data capture in free-living conditions, without changing behavior patterns.

Conclusion

Digital health interventions have a tremendous potential to bridge geographic, economic, and social disparities by leveraging ubiquitous tools that are accessible to Indigenous youth in rural and remote communities of the world. The Smart Indigenous Youth initiative embeds a digital health intervention into school curricula to integrate policies across systems. Moreover, this initiative empowers youth through culturally appropriate, land-based active living that is critical for their mental health. The Smart Indigenous Youth initiative provides a scalable and replicable model for digital health approaches that could be particularly effective in eventually developing policies to address the risk of mental illness in real time.

Acknowledgments

The principal knowledge users of the Smart Indigenous Youth initiative are the school principals, the File Hills Qu'Appelle Tribal Council, and the Saskatchewan Ministries of Health, Education, and Sport. The Youth Citizen Scientist Council is involved in implementing Smart Indigenous Youth, and in shaping school policies and programs. I am grateful to the youth and educator citizen scientists, and the staff and trainees of the Digital Epidemiology and Population Health Laboratory (DEPtH Lab) for their continuous support. I acknowledge the Canadian Institutes of Health Research for their support to the DEPtH Lab and the Smart Platform. The funding for this research is being provided by the Canadian Institutes of Health Research's Project Grant (#153226).

Conflicts of Interest

None declared.

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Original Paper

Repeated Psychosocial Screening of High School Students Using YouthCHAT: Cohort Study

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Abstract

Background: Psychosocial problems are common during adolescence and can have long-lasting effects on health and on academic and social functioning. YouthCHAT, an electronic HEEADSSS (home, education, eating, activities, drugs and alcohol, suicide and depression, sexuality and safety)-aligned instrument, has recently been demonstrated to be an acceptable and effective school-based psychosocial screener for 13-year-old (Year 9) high school students.

Objective: This study aims to compare acceptability and detection rates with repeated YouthCHAT screenings of high school students when they are 13 years old (Year 9) and 14 years old (Year 10).

Methods: We invited all Year-10 students to complete a YouthCHAT screening in 2018. Rates of positively identified issues were compared between the subset of students screened in both 2017 and 2018. Student acceptability toward YouthCHAT was investigated through focus group sessions. Onward clinical referral rates in 2018 were also investigated to explore the potential referral burden following screening. Data analysis for rates of positively identified issues were conducted with the McNemar test. Chi-square, Fisher exact test, and Kruskal-Wallis test were used to analyze the focus group data.

Results: Of 141 eligible Year-10 students, 114 (81%) completed a YouthCHAT screening during 2018, and 97 (85%) of them completed it for a second time. Apart from depression, which increased (*P*=.002), and perceived life stress, which decreased (*P*=.04), rates of identified issues were broadly similar between 13 and 14 years of age. Repeated screenings via YouthCHAT was acceptable to students and time-efficient (mean, 6 minutes and 32 seconds) but did not reduce the overall number of individuals with identified issues. Onward clinical referrals from positive screens were mostly managed by school-based health services without the need for external referrals.

Conclusions: Although further evaluation is needed, our results support the value of YouthCHAT as an acceptable and effective instrument with which to achieve routine identification of psychosocial issues and early intervention within a high school environment.

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KEYWORDS

mass screening; mental health; school health services; eHealth

Introduction

Adolescence is a period of great change and new challenges, when young people aged 13-18 years may experience psychological challenges that result in either distress or disorder [1]. These challenges can have a short-term impact on their general health, academic functioning, and relationships, and a longer-term impact on their adult functioning [2-4]. Almost half of adult mental health issues originate during adolescence, and early intervention can make a difference to their long-term trajectories [5,6]. Young people often find it hard to seek help, partly due to limited health literacy and the stigma of attending mental health services [7,8]. Many clinicians have also been found to lack the resources to identify psychosocial problems due to a lack of time, a lack of confidence, and concerns about the over-identification of problems for which personal management skills and access to services may be limited [9]. Although routine screening for psychosocial problems has been recommended for many years [10], until recently, this has not been feasible, primarily due to the lack of a suitable instrument that could identify the range of psychosocial issues faced by young people. Instead, opportunistic screening has been undertaken in schools and clinical settings using cumbersome and psychometrically invalidated face-to-face assessments such as the HEEADSSS (home, education, eating, activities, drugs and alcohol, sexuality, suicide and depression, safety) interview [11].

In New Zealand, routine psychosocial screening of high school students is undertaken using the HEEADSSS assessment. However, due to financial constraints, this is restricted to Year-9 students (13 year olds) in low decile schools [12]. In a typical high school, one or two school nurses take 6-12 months to complete these assessments [12]. Although completion rates are reported to the New Zealand Ministry of Health, outcomes of these assessments are neither reported nor published.

Our research group in Auckland, New Zealand, developed an electronic psychosocial screener called YouthCHAT (Youth version, Case-finding and Help Assessment Tool) to be used with young people (aged between 13-25 years), based on the adult screener CHAT [13] and its electronic version, eCHAT [14]. It comprises 13 modules designed to align with the HEEADSSS interview and includes 3 validated screeners, for anxiety [the GAD-7 (7-item instrument for Generalized Anxiety Disorder)] [15]; depression [PHQ-A (Patient Health Questionnaire–Adolescents)] [16]; and substance misuse, such as smoking, drinking, and recreational drug use [SACS (Substances and Choices Scale)] [17]. Other domains covered by YouthCHAT are problematic gambling, general stresses, behavior problems, eating problems, exposure to abuse, sexual health, anger management problems, and physical activity [14]. For each positive screen within a domain, a help question appears, which asks participants if they would like help today or later. The help question provides an opportunity for young people and their health providers to further discuss any issues that young people may want to address, thereby enhancing mutual decision-making. YouthCHAT is designed to be accessed as a website by health providers who have secure access to it. Once a YouthCHAT screen is completed, a summary report is generated for the health provider to review [12].

A counter-balanced randomized trial comparing YouthCHAT and the HEEADSSS assessment was conducted in a low decile Auckland high school with 13-year-old (Year 9) students in 2017. The study was registered with the Australian New Zealand Clinical Trials Registry (ANZCTR) ACTRN12616001243404p and was approved by the New Zealand Northern Region Ethics Committee (16/CEN/137/AM03). The study found that YouthCHAT was twice as fast to complete as the HEEADSSS assessment, as effective at identifying key psychosocial problems, and acceptable to both students and school nurses [12].

Due to the emergence of psychosocial problems across the whole of adolescence, it is likely that single episode screening, particularly when focused at its onset, will fail to identify the majority of problems faced by young people. We have previously proposed routine school-based screening as part of an annual health check to maximize the chance of early identification of psychosocial problems and normalize psychosocial screening within the context of a holistic health assessment. While YouthCHAT has shown promise as a psychosocial screener, its suitability for repeated use within a high school or other settings is currently unclear. Therefore, we decided to use YouthCHAT to rescreen the same cohort of 14-year-old (Year 10) students who were previously screened with YouthCHAT at 13 years of age in 2017, in the same high school [12]. Due to concerns about the potential burden on health services from positively screened individuals, we also planned to explore the nature of onward clinical referrals required by the group in 2018.

This study was designed to (1) provide novel insights into the acceptability of repeated screenings of high school students using an electronic screener such as YouthCHAT; (2) provide information on differing rates of psychosocial problems between 2 consecutive years (to see if rates increase with age, as might be expected during adolescence, and to see if being positively screened or receiving early intervention in 2017 was associated with a reduction in the severity of symptoms in 2018); and (3) provide information about resulting clinical referrals.

Our specific aims were to (1) compare acceptability and detection rates with repeated YouthCHAT screenings of high school students when they were 13 years of age (Year 9) and 14 years of age (Year 10), and (2) examine where onward clinical referrals were provided to those with identified needs.

Methods

Participants

All Year-10 (14- to 15-year-old) students at a low decile high school in Auckland, New Zealand, who had previously taken part in a YouthCHAT study in 2017 in Year 9 (at 13 to 14 years of age) [12] were invited to participate in this study, following the provision of paired informed individual assent and parental consent. No students were excluded. A subset of 20 students was invited to participate in a series of focus groups, during which verbal and written feedback regarding their use of YouthCHAT was obtained.

Procedure and Instrumentation

Written informed consent from students and paired assent from parents were obtained using paper forms. As some students had left and others had arrived between 2017 and 2018, only a subgroup of the total sample consisted of paired participant data from the same students screened in both years. Differences in acceptability of repeated screenings and changes in rates of identified psychosocial problems were analyzed in this subgroup.

YouthCHAT screening was completed on a tablet device with a Wi-Fi connection to the YouthCHAT website in the school health center over an 8-month period, between April and November 2018. A series of 4 focus groups with between 5-10 participants each was conducted on school premises in November 2018 to obtain written and verbal feedback from a subset of students who had been invited to take part by the school nurse, based on their interest and availability.

Encrypted YouthCHAT results were manually extracted and securely stored on a University of Auckland server as per New Zealand Northern Region Ethics Committee (16/CEN/137/AM03) requirements. Student demographic and postscreening referral data were also manually extracted from Medtech (a locally utilized patient management software system) and securely stored on the University server. Written feedback from focus group participants was collected on paper forms and securely stored on University premises. Audiotaped feedback from focus group participants was transcribed by an agent who had signed a confidentiality agreement, and electronic audio-files were securely stored on the University server.

Outcomes

Psychosocial problems from YouthCHAT were measured by positive responses to any items. Substance misuse was measured by positive responses to A Stop Smoking In Schools Trial (ASSIST) [18] or the Substances and Choices Scale (SACS). Problems with eating were determined by positive responses to any items in the eating module. Mental health and distress were measured by positive screens to the PHQ-A or GAD-7 scale. Life stresses were measured by positive responses to questions regarding different stresses such as the following: issues at home, school, or work; money; or relationships with specific people in one's life. Sexual health was measured by positive responses to concerns regarding sexual orientation, risky sexual behavior, or exposure to unwanted sex. Safety was determined by positive responses to either the anger or abuse modules, and to being bullied or exposed to violence in the stress module. Physical inactivity was measured by negative responses to regular physical activity engagement.

Data Analysis

Data were analyzed using Microsoft Excel (version 15.0; Microsoft) and Statistical Package for the Social Sciences (SPSS; version 25; IBM Corp). The YouthCHAT screening was considered positive if any items were acknowledged within each module. The depression, anxiety, and substance misuse modules were further examined to ascertain the severity of the results (rated as subthreshold, mild, moderate, or severe, according to the developers of the PHQ-A, GAD-7, and SACS). Analysis of paired data (for those who completed YouthCHAT in both 2017 and 2018) was conducted using the McNemar test for categorical variables. Focus group data from 2017 and 2018 were treated as independent groups. Responses to items regarding YouthCHAT and its use were analyzed using chi-square or Fisher exact tests to compare categorical variables; the Fisher exact test was used where there were any expected cell counts less than 5 [19]. The Kruskal-Wallis test was used for continuous or ordinal variables.

Results

Description of Participants

Of 141 eligible students, 114 (80%) were screened in 2018; incomplete data for 1 screening provided a total sample size of 113 for analysis in 2018 and 129 (93%) out of 139 in 2017. None of the invited students declined to take part in the study. A subset of 97 students who completed YouthCHAT screenings in both years were compared. In regard to participant ethnicity, of the paired subset, 60 (62%) students were Pacific Island, 24 (25%) were Maori, 1 (1%) was New Zealand European, 1 (1%) was Middle Eastern/Latin American/African, and 11 (11%) were of other ethnicities. The number of men (50/97, 52%) and women (45/97, 46%) in the paired subset were relatively similar, with 2 students (2%) identifying as gender diverse (which was an additional option in the 2018 YouthCHAT screener). Of the 20 participants invited to take part in focus groups, 16 agreed to do so. The self-reported demographic details of the 16 students who attended the focus groups were as follows: 5 men (31%), 9 women (56%), and 1 gender-diverse individual (6%); 7 (44%) were of Maori descent, 5 (31%) were of Pacific Island descent, and 3 (19%) were of other ethnic descent. Demographic details for 1 participant are unknown as they did not complete the attendance sheet.

Time Taken to Complete YouthCHAT and Time Period Between Screens in Paired Subset

The average time taken to complete YouthCHAT in 2018 was 6 minutes and 32 seconds (range, 2 minutes and 13 seconds to 16 minutes and 45 seconds). This was similar to the 8 minutes and 57 seconds (range, 1 minute and 45 seconds to 54 minutes and 15 seconds) taken by students in 2017. The Wi-Fi connection was lost for some students in 2017, which may explain the outlier of 54 minutes and 15 seconds. The average time period between the YouthCHAT screens in 2017 and 2018 was 11.4 months (range 6-18 months), with the time periods varying for each student from the paired subset.

Overall Detection Rates and Comparison of Results in a Paired Subset Between 2017-2018

Overall rates of detection of psychosocial problems and a comparison of results between 2017 and 2018 are presented in Table 1. The table displays the number of students who were positive for psychosocial problems in both years and the number of students who remained positive for the particular psychosocial problem in the repeated screening. It also represents the number of new positive screens for psychosocial problems in the following year of YouthCHAT screening. There was a statistically significant reduction in the rate of perceived life stress (-13%; 95% CI -25.1% to -1.0%; *P*=.04), a statistically nonsignificant increase in the rate of substance misuse, and a statistically significant increase in the rate of depression (18.8%; 95% CI 6.8-30.7; *P*=.002) between the 2 years. According to the 2018 PHQ-A scores, of the 96 respondents, 25 students had subthreshold depression, 3 students had mild depression, 4 had moderate depression, 4 had moderately severe depression, and 1 had severe depression. Otherwise, rates of psychosocial problems between these screening events were broadly similar, with concerns about weight and eating, and behavior and anger, being the most reported issues. Of the 90 students who self-identified with anxiety via the GAD-7 in 2018, 7 had subthreshold anxiety, 11 had mild anxiety, 7 had moderate anxiety, and 1 had severe anxiety. In regard to SACS scores, 8 students had scores greater than 2, indicating they required further assessment; 3 had scores greater than 4, indicating clinically significant problems; and 3 had scores greater than 6, indicating serious problems. Of the 5 students who screened positive for depression in 2017 and 2018, 3 had changed from severe to moderately severe symptoms, 1 remained unchanged with mild symptoms, and 1 had changed from moderate to moderately severe symptoms. Of the 8 students who screened positive for anxiety in both 2017 and 2018, 3 had changed from severe to moderate/mild, and 6 remained unchanged with either mild or subthreshold symptoms.

Table 1. Change in detection rates between 2017 and 2018 for students who completed YouthCHAT screenings in both years (n=97).

YouthCHAT domain	Total responses, N (%)	Total positive in 2017[a], n (%)	Total positive in 2018[a], n (%)	Remained positive in 2018 (% of those positive in 2017)[b], n (%)	New positive screens in 2018 (% of those not positive in 2017)[a], n (%)	Difference in proportions positive in 2017 & 2018 (95% confidence interval)	*P* value[c]
Smoking	94 (97)	9 (10)	13 (14)	6 (67)	7 (7)	4.3 (-3.4 to 11.9)	.34
Drinking	92 (95)	5 (5)	10 (11)	3 (60)	7 (8)	5.4 (-2.0 to 12.8)	.18
Drugs	92 (95)	6 (7)	12 (13)	5 (83)	7 (8)	6.5 (-0.4 to 13.5)	.07
Eating disorder	95 (98)	93 (98)	94 (99)	92 (99)	2 (2)	1.1 (-3.6 to 5.7)	>.99
Depression	96 (99)	12 (13)	30 (31)	5 (42)	25 (26)	18.8 (6.8 to 30.7)	.002
Self-harm	93 (96)	6 (6)	5 (5)	2 (33)	3 (3)	-1.1 (-7.7 to 5.6)	>.99
Anxiety	90 (93)	20 (22)	19 (21)	8 (40)	11 (12)	-1.1 (-12.7 to 10.4)	>.99
Stress	92 (95)	29 (32)	17 (19)	9 (31)	8 (9)	-13.0 (-25.1 to -1.0)	.04
Behavior	92 (95)	53 (58)	48 (52)	36 (68)	12 (13)	-5.4 (-17.9 to 7.1)	.46
Sexual health	92 (95)	21 (23)	16 (17)	9 (43)	7 (8)	-5.4 (-15.7 to 4.9)	.36
Abuse	85 (88)	19 (22)	12 (14)	5 (26)	7 (8)	-8.2 (-19.8 to 3.4)	.19
Anger	85 (88)	33 (39)	32 (38)	19 (58)	13 (15)	-1.2 (-14.3 to 12.0)	>.99
Physical inactivity	88 (91)	37 (42)	26 (30)	17 (46)	9 (10)	-12.5 (-25.3 to 0.34)	.06

[a] The denominators (N) are represented in the "Total responses" column.

[b] The denominators for this column vary, as they are the total individuals screened positive to the YouthCHAT domains in 2017.

[c] *P* value from the McNemar test.

Acceptability of Repeated Screening Using YouthCHAT

In 2018, the 16 students who took part in the focus group gave YouthCHAT a rating of 7.8 (range 5-10) on a point scale from "lame" to "awesome;" they also said it had been helpful for discussing psychosocial issues with their school nurse or doctor at a rating of 7.8 (range 5-10) on a 10-point scale from "not helpful at all" to "helpful." Although many (10/16, 63%) denied disliking any YouthCHAT questions, 6 of the 16 students (38%) said they did not like answering questions related to sexual health, substance misuse, exercise, anger, gambling, and depression. The results of student rating scores from both 2017 (n=10) and 2018 (n=16) are presented in Tables 2 and 3; they were not paired, as different groups of students attended the focus groups in each year. Overall, there were no major differences in the acceptability of YouthCHAT from one year to the next. Although fewer students said they had time to think about their responses in 2018, there was a notable reduction in feelings of embarrassment about discussing results with the school nurse, and a similar number of students reported comfort with disclosing things they would otherwise have not mentioned in both years.

Table 2. Comparison of student acceptability of YouthCHAT in 2017 (n=21) and 2018 (n=16).

Rated item	YouthCHAT in 2017 (n=21), n (%)	YouthCHAT in 2018 (n=16), n (%)	Change 2017-2018, *P* value
Works for people my age	18 (86)	10 (63)	.14[a]
I have time to think about my responses	16 (76)	7 (44)	.04
I felt safe answering the questions	14 (67)	9 (56)	.52
I talked about the things I wouldn't have mentioned	11 (52)	2 (13)	.01
It's easier to open up about my unhealthy behaviors and feelings	13 (62)	12 (75)	.40
It helped me identify the unhealthy behaviors and feelings I need help with	14 (67)	7 (44)	.16
Allowed my nurse to know about the unhealthy behaviors and feelings	13 (62)	8 (50)	.47
Has too many questions	6 (29)	3 (19)	.70[a]
Questions are too personal	5 (24)	1 (6)	.21[a]
I worried about the privacy of my information	9 (43)	3 (19)	.12
Takes too long	4 (19)	4 (25)	.71[a]
Questions were difficult to understand	2 (10)	2 (13)	.37
Questions did not relate to me	1 (5)	0 (0)	>.99[a]
Is boring	2 (10)	3 (19)	.63[a]
I felt embarrassed to talk to my nurse about my answers	6 (29)	0 (0)	.03[a]
My nurse was judgemental about things I opened up about	1 (5)	0 (0)	>.99[a]
Objected to specific questions			
Substance misuse	9 (43)	7 (44)	.96
Sexual health	8 (38)	6 (38)	.97
Safety	6 (29)	1 (6)	.11[a]
Physical inactivity	2 (10)	1 (6)	>.99[a]
Gambling	0 (0)	1 (6)	.43[a]
Depressed or low	0 (0)	2 (13)	.57[a]
Anger control	0 (0)	1 (6)	.43[a]

[a] *P* value for YouthCHAT items from Fisher exact test; the remaining *P* values are from the Pearson chi-square test.

Table 3. Focus group ratings of YouthCHAT in 2017 (n=10) and 2018 (n=16).

Rated item on a 10-point scale	YouthCHAT in 2017 (n=10), mean (range)	YouthCHAT in 2018 (n=16), mean (range)	Change 2017-2018, *P* value[a]
YouthCHAT helpfulness: "not helpful at all" to "helpful"	8.2 (5-10)	7.3 (3-10)	.57
YouthCHAT appraisal: "lame" to "awesome"	9.0 (8-10)	7.8 (5-10)	.33

[a] *P* value for YouthCHAT rating from Kruskal-Wallis H test.

Onward Clinical Referrals From YouthCHAT Screening

Table 4 presents the number of students who were referred to internal school health staff, health services, and programs following the YouthCHAT screening in 2018. Onward clinical referrals were made by the school nurse based on the severity of the psychosocial issue (eg, a concerning score from the PHQ-A questionnaire) and whether school health staff were already seeing the student who screened positive for any psychosocial problems prior to the YouthCHAT screening. As evident from Table 4, most students with positive YouthCHAT screens who received onward clinical referrals following school nurse review of their results were seen by school-based practitioners, particularly nurses and counselors. Only a few required assistance from external community-based or specialist health services. All students referred for onward clinical referrals had positive YouthCHAT screens, and most of those with depression (12/113, 11%), anxiety (19/113, 17%), and substance misuse (11/113, 10%) had clinically significant levels of symptoms.

Table 4. Referrals to school staff or youth development services for 113 students screened with YouthCHAT in 2018. (Note: some onward clinical referrals to school health staff or external services overlap due to multiple referrals for some students.)

Psychosocial issue	No onward clinical referral required, n (%)	Referrals to internal school staff			Referrals to external agencies and programs	
		Nurse, n (%)	Counselor, n (%)	Social worker, n (%)	n (%)	Type of referral
Depression	100 (88)	1(1)	13 (12)	N/A[a]	2 (2)	Specialist mental health service
Self-harm	104 (92)	1 (1)	9 (8)	N/A	N/A	N/A
Anxiety	97 (86)		16 (14)	N/A	N/A	N/A
Substance misuse	96 (85)	1 (1)	8 (7)	N/A	11 (10)	Addiction program
Sexual health	89 (79)	11 (10)	17 (15)	N/A	N/A	N/A
Eating/ exercise	95 (84)	1 (1)	3 (2.6)	N/A	15 (13)	Fitness program
Behavior concerns	95 (84)		17 (15)	N/A	1 (1)	Behavior support service
Safety	77 (68)	1 (1)	34 (30)	N/A	2 (2)	Anger management counseling agency
Stress	85 (75)		21 (19)	11 (10)	N/A	N/A

[a] N/A: Not applicable.

Discussion

Principal Findings

Our results demonstrate that YouthCHAT remains an acceptable, efficient, and effective HEEADSSS-aligned instrument for undertaking repeated psychosocial screenings with high school students. They also suggest that most identified problems can be managed within the school environment. Overall rates of identified issues at 14 years of age were not that different from those identified at 13 years of age, which may be unsurprising given the fact that most significant mental health issues emerge between midadolescence and early adulthood [20]. However, the relatively high rates of anxiety (21%, compared to 13% in a 15-year-old youths sample from a previous New Zealand study) and depression (31%, compared to 3% in 2017 and 6% from the same previous New Zealand study of 15-year-old adolescents [21]) in this study are interesting to note. These may partly be explained by the predominance of students of Pacific Island ethnicity and their known propensity to experience twice the rates of these issues as other New Zealand youth [22]. Reasons for higher rates of these conditions in this group are not fully understood but may bear some relationship to culturally mediated values [23], status incongruity [24], and nonculturally related sociodemographic factors (such as social deprivation) [25].

Many of those identified with depression (42%), anxiety (40%), substance misuse (60-83%), and eating concerns (99%) at 13 years of age also screened positive at 14 years of age. Although it might seem like screening did not make a difference to later rates of these problems, the truth is probably more complex. This was a relatively small sample, and most students who screened positive for depression and anxiety experienced a maintenance or improvement in symptoms, which, in the context of naturally increasing rates and severity of these conditions, may indicate that earlier intervention had some clinical effect. Certainly, larger, more detailed, and longitudinal studies are needed to more accurately evaluate the value of routine screening in reducing the long-term prevalence of psychosocial problems and their associated disability. The fact that most onward clinical referrals were undertaken by school nurses and counselors underscores the role of YouthCHAT in supporting early intervention within students' natural environments. It also assuages the concern that routine screening increases the risk of further burdening stretched specialist mental health services [12].

Limitations

This study was conducted at the same high school as a previous study so that results between both years could be compared. However, this remained a convenience sample, and the generalizability of study results to other high schools remains to be proved. The inclusion of primarily Pacific Island and Maori students, who comprised the bulk of students in the examined class, is both a strength and a weakness. Although they comprise 11% and 20% of the New Zealand population, respectively, Pacific Island and Maori youth have higher rates of psychological issues, including depression and suicide [22]. They are also usually harder to reach, accessing specialist services at lower rates than other ethnicities [26,27]. Due to funding limitations, feedback was not collected from school nurses or counselors regarding their satisfaction with receiving referrals following repeated YouthCHAT screenings.

Conclusions

This study demonstrates the acceptability and effectiveness of the repeated use of YouthCHAT for students. The fact that the majority of positive screens to YouthCHAT were manageable within the school health setting supports the feasibility of routine psychosocial screening in the school environment and the likelihood of earlier intervention. YouthCHAT is available for use by schools and can be easily implemented by school nurses and counselors for opportunistic and routine psychosocial screening. Routine screening via YouthCHAT may lead to reduced costs compared with lengthy face-to-face clinical assessments and more timely interventions for students within the school environment.

Recommendations for immediate research include trialing YouthCHAT with older (15- to 18-year-old) students within the same high school to examine age-related trends, and evaluating differing acceptability and rates of psychosocial problems between low and high decile, urban and rural, and English and Maori immersion schools. International studies, with or without culturally relevant adaptation, and longitudinal studies to gauge the impact of earlier intervention following routine screening, would also be worthwhile. For the moment, YouthCHAT remains the only electronic psychosocial screener with evidence of its acceptability and feasibility for repeated use in any type of setting.

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Conflicts of Interest

FGS is the developer of YouthCHAT. The other authors have no conflicts of interest to declare.

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Abbreviations

GAD-7: 7-item instrument for Generalized Anxiety Disorder
HEEADSSS: home, education, eating, activities, drugs and alcohol, sexuality, suicide and depression, safety
PHQ-A: Patient Health Questionnaire–Adolescents
SACS: Substances and Choices Scale
YouthCHAT: Youth version, Case-finding and Help Assessment Tool

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Short Paper

Parents' Perceptions of Their Children's Engagement in a Consumer-Based Meditation Mobile App: Cross-Sectional Survey Study

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Abstract

Background: In the United States, nearly half (48%) of school-aged children experience sleep disturbance that results in less than the recommended sleep duration, which may negatively impact mental health and behavior. Mindfulness interventions may improve sleep and mental health in youth. However, there are gaps in the literature regarding how children (2-12 years) and adolescents (13-17 years) practice mindfulness and the extent to which they benefit from these practices.

Objective: The purpose of this study was to determine parents' perceptions of their children's engagement with a consumer-based mindfulness meditation app and the extent to which they believe their children have benefitted from using the app, particularly with regard to sleep.

Methods: This study is a secondary analysis of a cross-sectional survey in adult subscribers (N=11,108) to the mindfulness meditation mobile app Calm. Participants who indicated that they had a child or children younger than 18 years (2944/11,108) who used the Calm app were asked additional questions related to their perceptions of their children's engagement with Calm. Descriptive statistics were used to assess children's app engagement, and chi-square tests and binary logistic regression models were used to assess differences in children's usage based on gender and age.

Results: Among the survey respondents, approximately half of the parents (1537/2944, 52.21%) reported that their children used Calm. Children used Calm mostly for (1) sleep (1168/1537, 75.99%), (2) stress (491/1537, 31.95%), (3) depression or anxiety (430/1537, 27.98%), and (4) improvement of overall health (215/1537,13.99%). Older children were more likely to begin using Calm to reduce stress, depression, or anxiety, whereas younger children were more likely begin using Calm to improve sleep. Most children used Calm when lying down to go to bed (1113/1529, 72.79%). Children were most likely to use sleep stories at night (1144/1207, 94.78%), followed by music and soundscapes (749/1114, 67.24%), meditations (736/1120, 65.71%), and breathing exercises (610/1092, 55.86%). Nearly all parents believed that using sleep stories was helpful for their children's sleep (1090/1128, 96.63%), and the majority of parents felt that the other components were also helpful for their children's sleep (music and soundscapes [570/728, 78.30%], meditations [445/696, 63.94%], and breathing exercises [610/1092, 55.86%]).

Conclusions: To our knowledge, this is the first study to explore parents' perceptions of how their children or adolescents use a popular consumer-based mindfulness mobile app (ie, Calm). As the majority of children use the app for sleep, mindfulness meditation mobile apps should consider incorporating age-appropriate sleep content to meet the needs of this audience. More research is needed to confirm the feasibility and effectiveness of mindfulness meditation apps for improving sleep and mental health in children and adolescents.

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KEYWORDS

mindfulness; meditation; children; mental health; sleep; mHealth

Introduction

In the United States, half (48%) of school-aged children (6-14 years) experience sleep disturbance (eg, insomnia, nightmares, sleep walking) most nights of the week that results in less than the recommended sleep duration (ie, 9 hours) [1,2], which is an important public health problem [3,4]. Sleep difficulties often persist from early and middle childhood through adolescence and early adulthood [5], and they are predictive of neurodevelopmental, psychosocial, and behavioral health concerns in later life [1,6]. There is a need for tools that have the potential to improve children's sleep and downstream effects that poor sleep may have on emotional and behavioral outcomes.

Mindfulness is the practice of being intentionally engaged in the present moment with nonjudgmental awareness of one's thoughts, feelings, and sensations [7]. Studies have suggested that mindfulness interventions can lead to improvements in stress, mental health, and sleep in both adults [8] and youth [9-11]. Although there is growing interest in mindfulness-based activities for children (2-12 years) and adolescents (13-17 years) [12], especially in schools [13], there are substantial knowledge gaps in the ways that children and adolescents practice mindfulness and the extent to which they benefit from these practices, particularly in regard to sleep.

The increasing use of technology (eg, smartphones, tablets) in children's lives makes mobile apps a convenient way to deliver mindfulness-based interventions that support health and well-being [10]. Though the current evidence related to the engagement and efficacy of mindfulness-based mobile apps in children and adolescents is lacking, research suggests that mindfulness-based mobile apps may be beneficial for mental health in adolescents [14,15], and the online delivery of mindfulness interventions are often better attended or preferred than in-person delivery [15,16]. However, a recent review of 36 free mindfulness-based apps for children reported that most failed to achieve a good quality rating score [10]. There is clearly room for improvement in mindfulness apps for the benefit of children and adolescents. Considering the potential for mindfulness apps to help improve sleep and mental health, more research is needed to better understand how children and adolescents engage with popular mindfulness apps in order to better meet the needs of this audience. Therefore, the purpose of this study is to determine parents' perceptions of their children's engagement with a commercially available mindfulness-based app and the extent to which they believed their children benefitted from using the app, particularly with regard to sleep.

Methods

Overview

The findings presented in this paper were part of a survey conducted in adult subscribers to the mindfulness meditation app Calm (N=11,108) [17]. Subscribers were eligible for the survey if they (1) were at least 18 years old, (2) could read and understand English, and (3) had used at least one sleep component of the Calm app in the previous 90 days. Subscribers received an email inviting them to answer a survey regarding their use of Calm. Participants who had children younger than 18 years were also asked about whether and in what ways their child or children used Calm.

Measures

An investigator-developed survey was used to obtain information from parents about how their children used Calm (see Textbox 1 for a complete list of questions).

Textbox 1. Survey questions for parents.

1. Do your children use Calm?

- Yes
- No

2. What are the gender(s) of your children who use Calm?

- Boys
- Girls
- Other

3. How old are your children who use Calm?

4. Why do your children use Calm?

- Improve overall health
- Reduce stress
- Reduce depression or anxiety
- Improve sleep
- Other

5. When do your children use Calm?

- Within the 30 minutes after waking
- In the morning, but not within 30 minutes of waking
- In the afternoon
- In the evening
- At night, but not within 30 minutes of going to bed
- Within 30 minutes before lying down to go to bed at night
- While lying down to go to bed at night
- When I wake up during the night and I can’t fall back asleep

6. Which best describes how your children use Calm at night?

- I try to use Calm on a regular basis
- I sometimes/occasionally use Calm
- I use Calm only when I need it

7. How many times per week do your children use each component at night or in order to help with sleep?

- Sleep Stories
- Music/soundscapes
- Sleep meditations
- Meditations
- Breathing exercises
- None of the above

8. [Of selected components] Do you think that using each of the following components has been helpful for your children's sleep?

- Very much helpful
- Somewhat helpful
- Not noticeably helpful

Statistical Analyses

All analyses were conducted in IBM SPSS Statistics version 26.0 (IBM Corp). Descriptive statistics were used to assess children’s app engagement. Differences in children’s usage based on gender and age were assessed using chi-square tests and binary logistic regression models.

Results

Of the 11,108 survey respondents, 2944 (26.50%) reported having children younger than 18. Half of the parents (1537/2940, 52.28%) reported that their children used Calm (see Table 1).

On average, children who used Calm were aged 9.66 (SD 4.11) years (see Figure 1). Approximately 60.83% (935/1537) of parents had boys and 66.95% (1029/1537) had girls who used Calm. Boys using Calm tended to be younger than girls ($F_{1,710}$=19.91; P<.001; d=0.34).

Parents most often reported that the reason that their children started using Calm was to improve sleep (1174/1537, 76.38%), followed by reducing stress (493/1537, 32.08%), reducing depression or anxiety (427/1537, 27.78%), and improving overall health (216/1537, 14.05%). Parents of older children were more likely to report that their children began using Calm to reduce stress, depression, or anxiety, whereas parents of younger children were more likely to report that their children began using Calm to improve sleep (see Table 2). There were no gender differences in the reasons for using Calm.

Most parents reported that their children used Calm when lying down to go to bed (1113/1529, 72.79%). When using Calm at night, children were most likely to use sleep stories (1144/1207, 94.78%), followed by music and soundscapes (749/1114, 67.24%), meditations (736/1120, 65.71%), and breathing exercises (610/1092, 55.86%). Nearly all parents believed that sleep stories were helpful for their children's sleep (1090/1128, 96.63%), and the majority felt the other components were also helpful (music and soundscapes [570/728, 78.30%], meditations [445/696, 63.94%], breathing exercises [322/576, 55.90%]). Older children used meditations and breathing exercises more often than younger children, and girls used breathing exercises more often than boys (see Table 3).

Table 1. Characteristics of parents whose children used Calm.

Characteristic	Participants, n (%)
Gender	
Male	141 (10.14)
Female	1250 (89.86)
Ethnicity	
Hispanic	89 (6.46)
Non-Hispanic	1288 (93.54)
Race	
White or European American	1166 (78.31)
Asian or Asian American	49 (3.29)
Black or African American	35 (2.35)
American Indian or Alaskan Native	20 (1.34)
Hawaiian or Pacific Islander	6 (0.40)
Biracial or multiracial	58 (3.90)
Other race	66 (4.43)
Sleep difficulties	
Falling asleep	993 (64.61)
Staying asleep	631 (41.05)
Waking up too early	170 (11.06)
Getting a restful night's sleep	604 (39.30)
None	221 (14.38)

Figure 1. Age distribution of children using Calm.

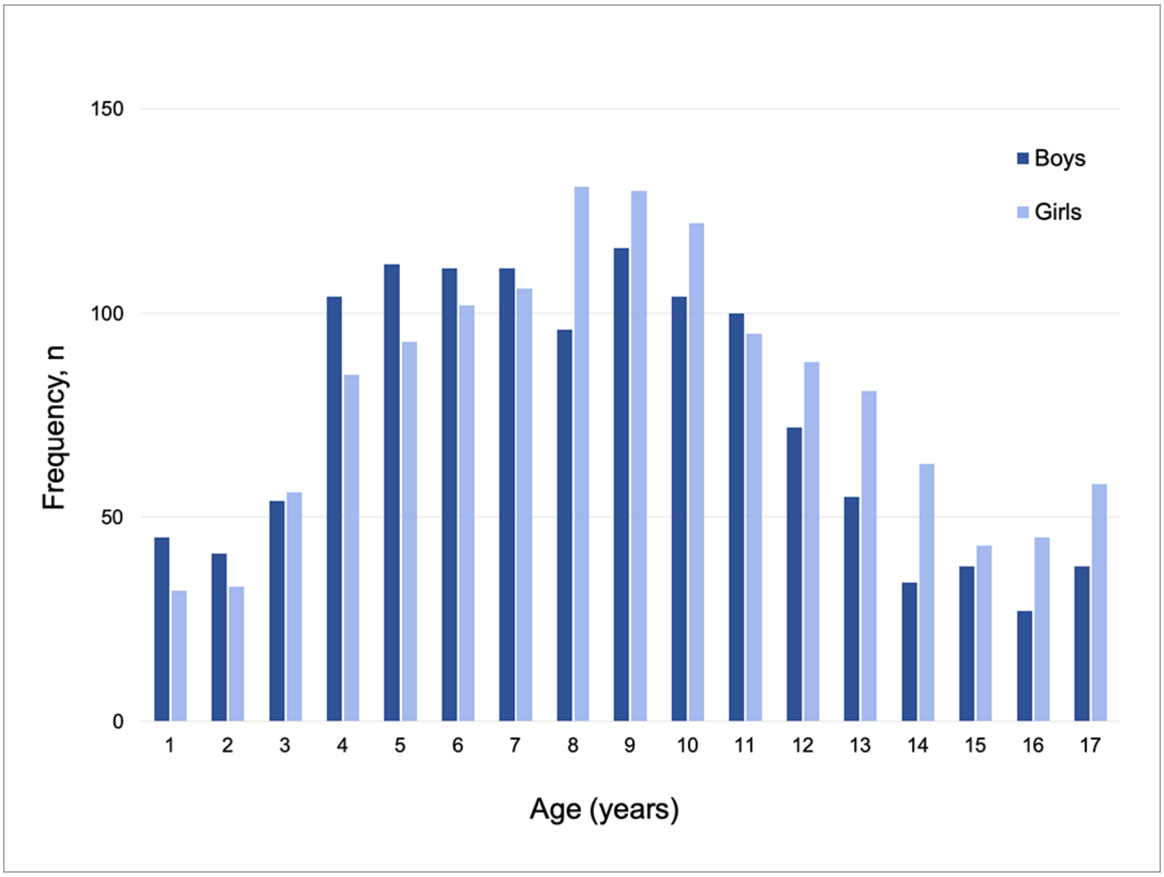

Table 2. Reasons for starting Calm by age (n=751).[a]

Reason	Coefficient (95% CI)	*P* value
Improve sleep		
Constant	5.73	<.001
Age	0.93 (0.90-0.97)	<.001
Reduce stress		
Constant	0.09	<.001
Age	1.18 (1.13-1.22)	<.001
Reduce depression or anxiety		
Constant	0.64	<.001
Age	1.20 (1.16-1.26)	<.001
Improve overall health		
Constant	0.11	<.001
Age	1.01 (0.96-1.06)	.82

[a] In all models, coefficients for constants reflect intercepts in the logistic regression models, which can be interpreted as the odds that parents endorsed the outcome (reason for using Calm) when the predictor (age) is equal to 0. Age was a continuous variable.

Table 3. Frequency of component usage by age and gender.[a]

Model	Coefficient	SE	*P* value
Component usage by age (n=751)			
Sleep stories			
Constant	3.58	0.26	<.001
Age	–0.4	0.03	.17
Music			
Constant	2.56	0.30	<.001
Age	–0.03	0.03	.29
Meditations			
Constant	0.57	0.25	.02
Age	0.09	0.03	<.001
Breathing exercises			
Constant	0.38	0.25	.13
Age	0.09	0.02	.001
Component usage by gender (n=717)			
Sleep stories			
Constant	3.14	0.16	<.001
Gender=female	0.28	0.22	.20
Music			
Constant	2.25	0.20	<.001
Gender=female	0.05	0.26	.84
Meditations			
Constant	1.29	0.16	<.001
Gender=female	0.26	0.21	.23
Breathing exercises			
Constant	0.91	0.16	<.001
Gender=female	0.48	0.22	.03

[a] In all models, coefficients for constants reflect intercepts in the regression models, which can be interpreted as the expected values of the outcome (weekly usage frequency) when the predictor (age, gender) is equal to 0. Age was a continuous variable. Gender was a dichotomous variable in which male was coded as 0, and female was coded as 1 (therefore, the intercept can be interpreted as the expected value for boys).

Discussion

Principal Findings

To our knowledge, this is the first study to assess children's engagement with the popular mindfulness app Calm and the potential benefits associated with its use. Most children who used Calm were elementary school aged (ie, 4 to 11 years), with similar rates of use in boys and girls. Older children were more likely to use Calm to reduce stress, anxiety, or depression compared with younger children, who were more likely to use Calm for better sleep. According to parents, children mostly used Calm at night, with sleep stories being the most popular component and the component perceived as the most helpful for their child's sleep.

Parents reported similar rates of app usage for boys and girls, but girls used the app longer (continued to use it with age). Research has shown that in adults, women meditate more, find it more enjoyable, and report greater benefits from it than do men [18]. Given that younger boys appear to be just as likely to meditate as younger girls, mindfulness-based apps may consider content that engages boys and will continue to engage them with age, given their needs and preferences as they get older.

Interestingly, older children and adolescents were more likely to begin using Calm to reduce stress, depression, or anxiety, while younger children were more likely to begin using Calm to improve sleep. Marked increases in stressors have been observed in children and adolescents as they age [19], which may also explain the greater likelihood of older children and adolescents using Calm for their mental health. Additionally, our data suggest that parents reported the usage of Calm in their children to decline around the age of 11 years, which also highlights the need for consumer-based mindfulness mobile apps to better meet the needs of children and adolescents (eg, age-appropriate content, peer support, resources).

Although this app was not exclusively designed for children, Calm provides child-specific content, and many parents use this app. This survey revealed that children use Calm for sleep, and potential positive effects in mental health may be observed. Future research should include randomized controlled trials to test the app's effectiveness in children.

Finally, as the majority of parents indicated that sleep was a primary reason their children used Calm and that their children used Calm when lying down to go to bed, these data highlight the need for mobile apps to target sleep in children and adolescents. Although sleep stories were appealing and helpful, older children were also likely to use meditations and breathing exercises to help them sleep. This suggests that app developers may want to create content appropriate for a teenage or adolescent audience and that mindfulness-based apps developed for children should incorporate strategies to improve sleep specifically.

Limitations

Though this was one of the first studies that explored parents' perceptions of their children's engagement with a commercially available mindfulness-based app, there are limitations. First, most of our sample was White and well educated. There is a need to explore perceptions in more diverse populations. Second, parents' perceptions of their children's engagement in the Calm app may be biased, especially in parents who used Calm for sleep, were generally satisfied with Calm, and reported it to be helpful for their sleep, as they may have perceived Calm to be more helpful compared with what their children believed. However, studies suggest that children, especially those younger than 7, are not able to respond accurately to self-reported behavior, and parents' perceptions may be more useful data [20]. Although children in this sample were older than 7, age was unknown before the survey was administered. Third, this was a cross-sectional survey, and therefore, we do not know the true effects of the Calm app for improving sleep in children.

Conclusions

This is the first study to explore how children and adolescents use consumer-based mindfulness mobile apps. These data are important, as they suggest that children, especially younger children, and adolescents of parents who engage in a mindfulness-based apps often use these apps for sleep and that as children get older, they are more likely to use these apps to for their mental health. However, more research is needed to confirm the feasibility and effectiveness of these apps for improving sleep and mental health in children and adolescents.

Conflicts of Interest

JH has been conducting investigator-driven research with Calm for over 5 years and is currently consulting as the Director of Science at Calm. As Director of Science, JH directs the Scientific Advisory Board, whose role is to ensure the quality of Calm's science. JH has no equity or stock in Calm and receives no financial incentives from the sales of Calm. All other authors declare no conflicts of interest.

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Original Paper

Qualitative Evaluation of Web-Based Digital Intervention to Prevent and Reduce Excessive Alcohol Use and Harm Among Young People Aged 14-15 Years: A “Think-Aloud” Study

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Abstract

Background: In the United Kingdom, despite some downward trends in alcohol use among young people, over one-fifth of young people reported excessive alcohol use in the past month, which is associated with short- and long-term harm to health. Digital interventions to reduce alcohol use, such as websites, among young people present an appealing and cost-effective mode of intervention that can be integrated into the education system. However, relatively few school-based digital alcohol-focused interventions have been developed and evaluated for young people in the United Kingdom.

Objective: This study aims to develop a novel web-based intervention, *Rethink Alcohol*, to prevent and reduce excessive alcohol use and related harm among young people aged between 14 and 15 years, and explore the views of young people, teachers, and youth workers in relation to the content, design, and usability of the intervention.

Methods: Intervention development followed the person-based approach, using theories of social norms and social influence. Qualitative “Think-Aloud” interviews, either one-to-one or paired, were conducted while participants perused and worked through the web-based intervention, talking aloud. Participants included 20 young people (12 female, 8 male), 5 youth workers (4 female, 1 male), 3 teachers (2 male, 1 female), and 1 (male) clinical professional, recruited via youth groups and professional networks. Interviews were audio recorded, transcribed verbatim, and analyzed thematically.

Results: The prototype web-based intervention included normative feedback, information, a quiz, interactive activities, and scenarios. On a rating scale of impressions from poor (1) to excellent (5), participants gave an average score of 3.6/5. A total of 5 themes were identified: content, credibility of the website, making the website easy to understand, design and navigation, and suitability for the audience. These themes reflected views that the content was interesting, credible, informative, and embodied a neutral and nonjudgmental tone, but stronger messaging was needed regarding social pressures and short-term risks regarding safety and risk behavior alongside clarity around pathways of risk; credibility and trustworthiness of information were critical features, determined in part, by the professionalism of design and referencing of sources of information provided; and messages should be succinct and come to life through design and interactive features.

Conclusions: Together, the data illustrated the importance and challenge of communicating nuanced alcohol-focused public health messages to young people in concise, clear, nonjudgmental, and appealing ways. Young people report interest in clear, credible, neutral, and interactive messages regarding social pressures and short-term risks of alcohol use via a web-based intervention. There is scope for optimization and feasibility testing of the *Rethink Alcohol* intervention.

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KEYWORDS

public health; adolescent; mobile phone; alcoholic intoxication; internet

Introduction

Background

Although downward trends have been observed in alcohol use among young people aged between 16 and 24 years in the United Kingdom, consumption is higher than for other age groups [1] and over one-fifth report being drunk, in the past month [2]. Digital technologies, such as smartphones, are increasingly integrated into behavior, lifestyle, and education. Approximately 90% of young people in the United Kingdom aged between 16 and 24 years, and 41% of those aged between 5 and 15 years own a smartphone [3,4]. As such, digital interventions could play an important role in changing behavior and reducing alcohol consumption in this group, thus contributing to preventing a range of alcohol-associated short- and long-term harm to health [5-10].

Evidence highlights that universal digital alcohol and other drug prevention interventions can be beneficial in reducing the frequency of alcohol or drug use among both young people and adults [11-18]. One systematic review demonstrated that engagement with personalized digital interventions that aim to reduce hazardous and harmful alcohol use among adults was associated with reduced consumption per week and one less binge drinking session per month, compared with controls [14]. Another review showed that alcohol-focused interventions reduced consumption among college students screening positive for hazardous alcohol use [13]. Across reviews, small but beneficial impacts have been demonstrated within universal and targeted interventions across a range of outcomes including number of drinks per drinking day, number of heavy drinking days, average weekly consumption, and frequency of binge drinking for participants from schools, health care settings, and the community [11,13,14,18,19].

Digital interventions may provide an appealing mode of intervention for young people, while being flexible, adaptable, person-centered, and cost-effective when delivered at scale over time [14,20]. In addition, technology and digital engagement are increasingly integrated into education, with evidence indicating a beneficial impact on educational outcomes if used appropriately to support learning and teaching [21]. The UK government recently published a strategy highlighting the ambition of integrating innovative technology into education to improve efficiency, remove barriers to education, and drive improvement [22].

To date, however, studies have mostly targeted young adults or the general population, and comparatively fewer digital interventions have aimed to reduce alcohol consumption among adolescents [23]. In addition, few universal school- or youth group-based digital interventions have been developed and tested using randomized controlled trials. Globally, 8 have focused on alcohol alone, but none were tested in the United Kingdom [15]. Although a digital intervention for young adults has been developed in England and acceptability was investigated [24], effectiveness has not been established [25,26] and none, to our knowledge, have investigated the development of a digital alcohol-focused intervention designed specifically for use in school and youth group settings.

Objectives

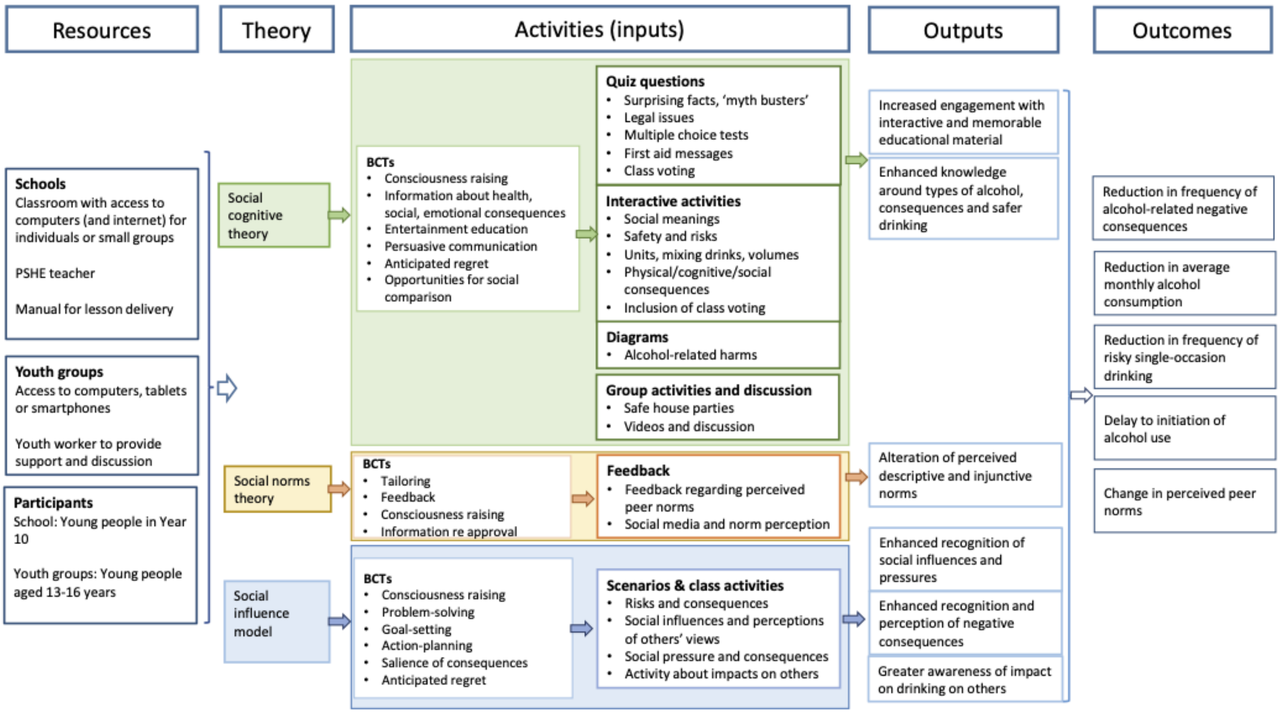
We aimed to develop a web-based intervention (*Rethink Alcohol*) to reduce excessive alcohol use among young people aged between 14 and 15 years. The intervention aimed to: (1) delay initiation of alcohol use (primary prevention) and (2) reduce the average amount of alcohol consumed per month (secondary prevention). Secondary aims were to reduce risky single occasion drinking, frequency of alcohol-related negative consequences, and changes in perceived injunctive and descriptive peer norms. Here, we report the theoretical basis and stages of intervention development, and the views of young people, teachers, professional experts, and clinicians regarding design, content, acceptability, usability, and implementation of the intervention in practice.

Methods

Development of the Digital Intervention

Development of the intervention *Rethink Alcohol* followed the person-based approach [27]. First, a scoping literature review of alcohol-focused digital interventions was conducted. Intervention components, content, duration, theory, and outcomes of alcohol-focused digital interventions for young people were examined, and behavior change techniques (BCTs) shown to be effective were noted [18]. BCTs form part of the *modelling* phase of complex intervention development, which involves hypothesizing *what* to target (behavioral determinants) and *how* to do this (techniques to change these determinants; [28]). Our previous qualitative studies with young people aged between 14 and 15 years, and 18 and 20 years [29,30] highlighted the peer, family, and socio-cultural influences of alcohol use, the behavior change required, and the behavioral and attitudinal challenges to be addressed by the intervention. Figure 1 shows our logic model for the intervention.

Figure 1. Logic model for intervention development. BCT: behavior change technique; PSHE: Personal, Social, Health, and Economic.



Throughout the process of intervention development, we engaged with 3 young people advisory groups (YPAGs): Generation R, ALPHA (Advice Leading to Public Health Advancement), and YPAG north east (YPAGNE). YPAGs provided feedback at each stage, which, alongside qualitative research findings, shaped the written content, activities included, design and layout of the prototype website, and considerations about implementation and use in practice. For instance, in workshops, young people highlighted content that should be included (eg, social pressures, drink driving, managing parties, injury, violence), design features that would be appealing (eg, using a unit calculator, voting on the types of images to include), and the appropriate tone to be used (eg, nonjudgmental, accepting language). Contribution from our steering group, which included 2 young people, also shaped the content. These processes informed the guiding principles of the intervention and its content, theoretical perspective, and design.

Rethink Alcohol was based on social cognitive theory, social norms theory, and the social influence model. Intervention components were designed to incorporate these theoretical perspectives and map BCTs to each component. The first version of the prototype website (v1.0) was created using the UXPin software (UXPin Inc). Feedback regarding v1.0 was obtained from YPAGs on topics covered, the written content, name of the website, activities to be included, design, layout and the types of images to use, navigability, tone, and how the website could be used in a classroom setting, enabling the development of a second-stage website (v1.1). Exemplar screenshots of the intervention website are shown in Multimedia Appendix 1.

In terms of content, the prototype website was structured around 4 themes: (1) Reality check: do people my age really drink alcohol? This section included questions regarding the perceived frequency of alcohol intake and getting drunk and feedback based on data from a survey of young people in England. An opportunity for goal setting was included. In addition, a quiz, including questions about alcohol content of different drinks, sugar content, mixing drinks, health consequences, and drink driving. (2) A "Get the facts" page provided information about alcohol and the law, drink driving, action of alcohol in the body, and health consequences. Facts were also included by theme, as advised by young people, so that information could be identified quickly, related to the themes of alcohol and health (addiction, accident and injury, sex and consent, hangovers, cancer, alcohol, and the brain); units, strength, and alcohol by volume; drinking and friendships (including social pressure, first aid); and guidelines for alcohol intake. (3) Top tips for staying safe included content regarding how to look after a friend whose had too much alcohol, the recovery position, guidelines, managing pressures, and sources of information and support (eg, addiction support). (4) Real life, which included scenarios that could be played out by choosing different options for action, such as a house party involving injury and sharing of photos, and outdoor drinking and violence. Our intention was to include videos prepared by young people, but this was not possible within the available timeframe; thus, a format representing messages communicated via social media was used.

Think-Aloud Study

Qualitative interviews were intended to gain an understanding of views regarding the breadth and relevance of content as well as views regarding navigability and design, hence guiding refinement and thus optimization of the prototype website. The findings will inform a second stage process of altering design and updating content to reflect the views obtained.

Participants

Young people, teachers, and youth workers were recruited purposively from youth groups and schools in Bristol and the surrounding area, aiming for diversity in socioeconomic status and alcohol use. Snowball sampling was employed to quickly access the target population. Young people were eligible for participation if they were between 14 and 18 years of age at the time of the study. Data from 3 paired interviews could not be included in the analysis owing to an error during fieldwork and individuals outside of the eligible age range (ie, older than 18 years) being included in these interviews. Although the intervention is targeted to young people aged between 14 and 15 years in the school environment, we anticipate that the website could be used in youth groups and other settings, which might include young people with a broader age range. We were also keen to recruit young people from youth groups to include a range of demographic groups from different geographical areas within the timescales of the study. Young people attending youth groups were typically aged between 16 and 18 years. In addition, we considered that it would be helpful to hear from those who are able to reflect on previous experiences and provide helpful feedback about information or support that would have been helpful at that time point in adolescence. The professional participants were approached through existing networks and contacted by email or telephone with an electronic copy of the information leaflet and summary of the study aim.

Procedures

Semistructured interviews guided by the Think-Aloud method [24,27,31] were conducted by the principal investigator (GM; female), SM (female), or other study staff, all of whom had experience of qualitative interviewing. Interviews were guided by a flexible topic guide and lasted approximately one hour, with the Think-Aloud component included at the start of the interview. The development of the topic guide was informed by related studies [25,31] and our focus was on understanding young people's views regarding content, design, and usability, as per feedback from YPAGs. Paired interviews (ie, between friends) were conducted if participants preferred. Although the think-aloud section of the interview aimed to identify participants' views and impressions while they used the website, what they were thinking about and feeling through the process, the semistructured section aimed to provide an opportunity to explore views around aspects of the website, such as perceived accuracy, presentation, appropriateness, and completeness of information provided, if these points had not been covered. The interviewer's role was to prompt the participant to keep verbalizing their thoughts on the website [24] to explore views on content (eg, the information on the website useful, clear, comprehensive), design (eg, views on the style, font, colors, layout of the website), and usability (eg, is the website easy to navigate). Participants were also asked what they thought of the interactive components included, such as quizzes, scenarios, and personal feedback. Interviews with teachers aimed to explore the applicability of the Personal, Social, Health, and Economic (PSHE) curriculum (eg, educational content, timing) and feasibility of implementation. Participants were made aware of the reason for conducting the study and the research team's interest in the topic.

Written informed consent was obtained from all participants and parental consent and a young person's assent obtained for those aged under 16. Adolescent participants were offered a £15 (US $19.88) gift voucher, and teachers and youth workers were offered a £25 (US $33.14) gift voucher to account for their time contribution. The disparity in payment between young people and teachers and professionals reflected the fact that teachers and professionals contributed their time in working hours. Ethical approval was obtained from the University of Bristol Faculty of Health Sciences Ethics Committee (Ref: 74270).

Analysis

Interviews were audio recorded using an encrypted recorder and transcribed verbatim. We undertook thematic analysis guided by Braun and Clarke [32], adopting a framework approach to organizing the data [33]. The coding framework was developed following the initial reading of a selection of transcripts by 2 researchers (Multimedia Appendix 2). One researcher then applied these codes to the transcripts, refining the codes, and adding new ones as data analysis progressed. Line by line open coding was used to assign qualitative codes to sections of the data that were reflective of that code [34]. The codes were discussed to determine if any extracts needed to be moved, if codes needed more refinement or additional codes should be considered, with disagreements resolved through discussion. Participants did not provide feedback on the findings. The themes presented in the results section represent the cumulation of the coding process. Coding and data management were conducted on NVivo 12.0 (QSR International).

Results

Think-Aloud Study

We interviewed 12 participants through single interviews and 17 participants in paired interviews (n=29). The core themes identified in the Think-Aloud study were (1) content, (2) credibility of the website, (3) make the website easy to understand, (4) design and navigation, and (5) suitability for the audience. A total of 26 participants, across all participant groups, gave an overall score out of five for the website ranging from scoring 5 (excellent) and scoring 1 (terrible) with a mean score of 3.63, indicating that they thought the website was good, but some improvements were required. The design of the website was not as anticipated, and many participants appeared to let down by this aspect, which was reflected in their scores. The data obtained from paired interviews did not appear to differ substantially from the data obtained from single interviews. The themes in this section draw upon suggestions for improvement as well as insights about adolescence and alcohol use that were relevant for the development of the intervention prototype.

Content

In general, participants felt that there was an appropriate amount of content, that the content was accurate and interesting, and that the website was informative. Most of the comments about the content related to how it could be more engaging, if the content should be moved to a different area of the website and ideas for additional content.

Although the content included in the website had been strongly informed by YPAGs, several participants thought there should be more on the website about the consequences of being drunk beyond health implications, such as engagement in risky behaviors (such as taking drugs or swimming in a canal), potential dangers of sexual assault, drink spiking, and getting home safely. This was connected to the idea of preparing young people for what to expect if they choose to get drunk for the first time. Several participants thought there should be signing to support information related to these wider issues in addition to those already included. A common suggestion was to incorporate information about wider risks in the *scenario* section, which many participants engaged with:

> *Maybe you could have a scenario about someone's drunk, and they're about to have sex or kiss, or something like that. Having a scenario about that, asking, 'Is this appropriate when they have drunk stuff and I have drunk stuff, or they have drunk loads and I have not?'* [Participant RO4, young person]
>
> *Probably, a little bit more around risky behavior, and that just the increases of risky behavior...Your risky behavior, but also the behaviors of other people that can become risky.* [Participant R03, youth worker]

These comments about additional content are mostly related to being drunk and social situations. Addiction was mentioned by some participants, which while included on the website, indicated that young people think an alcohol intervention should have an awareness of a range of risks. Some participants thought that *scenarios* on the website could form a broader discussion in the classroom around more complex issues such as decision impairment and risky behaviors. These topics are already discussed in PSHE lessons and are perhaps more immediate concerns of young people than the long-term impacts of alcohol on health:

> *You say, "Well, it's happened more than you'd think," and it's not like you want to show them CCTV, but sometimes there are incidents where they have the movements of that person, and they were on their own. Then that starts another conversation, "Well, why were they on their own? Okay, what happened? Why were they making the wrong decisions, what made them think it would be alright to go in the water?" You know, and then you might get onto, "Oh, well, they were showing off because they were drinking alcohol,"* [Participant R09, teacher]

In addition to wider risks, most participants saw peer pressure and social influence as important considerations. Some thought that enhancing peer pressure sections on the website would be useful:

> *It gives you the information, but it does not really say what you can do. It just says 'your friends will respect you for being true to yourself,' that's not always the case. Maybe write an alternative like, 'if they do not, it's not healthy. Get out of the group," sort of thing. If they stay in the group thinking their friends will respect them, that is not always the case.* [Participant RO20, young person]
>
> *I like the little bit of text at the top that sort of summarises the concept of peer pressure… do not want to drink but I feel like I need to fit in with everyone.* [Participant RO27, young person]

Most participants had positive comments about the quiz section of the website, with almost all participants taking the quiz first. Some suggested that discussing the sugar content of alcohol was a good approach to engaging young people, who may be health conscious but may not have associated alcohol with high levels of sugar. A few participants thought that this section should go further to talk about calories and how alcohol can affect muscle mass.

Overall, participants were generally positive about the content of the website. There were comments about additional areas of importance that could be included, which centered around wider risks and peer pressure. Such issues were thought to be best addressed through interactive elements of the website, such as the scenarios and the quiz.

Credibility of Website

The credibility, accuracy, and trustworthiness of the website appeared to be crucial for the sample. Most participants thought that the website was a credible and trustworthy source of information based on positive comments about the homepage and fact pages. However, some participants assumed that the information was accurate and from a credible source as it *comes from the university*, indicating that their involvement in the study had resulted in some preconceived ideas. Several participants thought the *look* of the website was critical for credibility, suggesting that a *professional* and *consistent* design would make a website more trustworthy. Simple design elements such as having the same font throughout, the same style of images and using *modern* colors were thought to add a sense of professionalism and therefore enhance trustworthiness and credibility:

> *I think you have got a lot of relevant stuff here, not all of it relevant, and I think the presentation just could be a bit more professional. I think it's coming along quite nicely.* [Participant RO1, young person]
>
> *If you clicked on different things, it was not different colours or themes. I thought that it also adds to it. Like trustworthiness, like thought has been put into its design.* [Participant RO5, young person]

References with links and source information after facts were mentioned by a few participants as things they looked for when establishing the credibility. Some also mentioned the idea of a kite mark or logos of sources from which the information was gathered, as these are things they would generally look out for when viewing a website:

> *I think there is also a slight bit of distrust if things have not been referenced.* [Participants RO11 and RO12, young people]

The professional interviewees stated that young people question all the information they receive and are typically critical of where information comes from. Referencing is even more crucial if the facts or statistics are surprising to the young people, such as "23% of 15-year-olds have been drunk in the last month" [35]. One professional participant mentioned that they would expect young people to ask for the source of facts during classroom discussion. Having an easily accessible source reference allows the session to flow better and gives the teacher or youth worker confidence in referencing the facts:

> *If I was using this resource with young people, it might just be nice to know where that came from, from a professional angle. So young people might come and ask that question and say, "Well, where have they got that from? How do they know that?" So we can just say, "Oh, it was a study by X, Y, Z."* [Participant R03, youth worker]

Maintaining these elements thought to enhance credibility could help young people engage with the content easily, as no time is spent questioning the sources and trustworthiness of the website. Overall, trustworthiness, credibility, and accuracy are important to young people and can be achieved through consistent and professional design elements as well as clear transparency around where information comes from.

Make the Website Easy to Understand

This theme was organized around 3 subthemes: (1) clarity, (2) levels of complexity, and (3) quantity.

Clarity was important to participants, as discussed by both young people and professionals. Clarity might be achieved through wording, phrasing, and consistency of units, such as for alcohol strength:

> *Obviously, a big bottle of a cider, depending on the size, will have more units of alcohol in than a single shot, so that's a little bit of a confusing message, perhaps.* [Participant R03, youth worker]

> *I feel like the question is somewhat unclear. This could mean whether they had too much alcohol this one specific time and they're drunk, or if they frequently have too much alcohol and they have a problem.* [Participant RO15, young person]

Using specific brands or sizes of bottles may be one strategy to limit misinformation. Here participants highlighted the potential for confusion by using generic terms such as *alcopops* or *bottle of cider* as there is a wide range of types, sizes, and alcohol strengths. If participants are clear about which drink is being referred to, young people may be able to engage with the content better and learn how drinks compare in terms of alcohol strength, with less time spent questioning what the drink is. One professional mentioned that *alcopops* are not very popular with young people, which was reflected in a few young participants not knowing what *alcopops* are.

There were also examples of complex ways in which alcohol could affect people, with careful thought needed to describe them to avoid giving the wrong information. An example of this is outlining diseases that can result from alcohol consumption. One professional participant addressed how wording could be misleading around the risk of sexually transmitted infections (STIs). They highlighted the need to outline how alcohol-associated behaviors could increase risk rather than the alcohol itself being the direct cause of STIs. Other examples include the need for clarity around the connection between energy drinks and alcohol, and how mixing these drinks may lead to other risky behaviors, as young people may not have considered them to be linked. Finally, more explanation was suggested around how alcohol may increase the likelihood of engaging in a fight, which was a source of confusion for a few participants. One suggestion for adding clarity here was to discuss how alcohol can affect how people make choices, as this is frequently discussed in PSHE lessons.

The quantity of information, namely instances where there was too much written information on a page, was important to both young and professional participants. Although repetition might not impact understanding and some repetition allows information to be received quicker, some participants noted too much repetition would mean that users lose interest. Similarly, *text heavy* pages may discourage young people from reading anything on the page at all. Several participants valued text boxes or bullet points broken up with images:

> *I think just the smaller quantity of text made it easier to understand for 14- and 15-year-olds.* [Participants RO18, young person]

This theme of quantity in turn links to getting the information quickly, which participants felt was important for some kinds of information more than others. For instance, finding out what to do if a friend is drunk is more time-sensitive than current statistics on age-group drinking.

The most mentioned concept in relation to the present theme was clarity. The quantity of text should be carefully considered, with text broken up by boxes, bullet points, or images. However, this should be balanced with clear descriptions of more complex pathways between alcohol use and outcomes.

Design and Navigation

Design was important to young people, with many providing positive comments about the design of the intervention, most commonly about the colors, fonts, and the home page. The most frequently mentioned design elements that young people valued were images and videos. Specifically, more *boring* or *serious* elements of the intervention, such as information pages, should have more images or diagrams than other pages. One participant suggested using an image of the body that users could click on to get facts:

> *Yes, again, more images rather than lots and lots of texts. Break it up a bit more. You know, maybe having pictures of a body and being able to draw lines off it saying stuff that's affecting this. Being able to click on different parts of the body…It just makes it a little bit more dynamic, I think.* [Participant R06, a youth worker]

Participants thought it was a combination of aesthetics as well as interactivity that engages young people in delivering health information. Others noted the importance of not having too many different things *going on* within one page. For instance, in contrast to feedback from YPAGs, it was considered that fact boxes should not interfere with their interaction with the quiz or scenarios. Participants also noted the importance of the website being easy to navigate, being able to reach where you wanted to with minimal clicks and with an understanding of where every link would take you. Many of the participants thought the home page was clear and it was easy to see where everything was. Participants also liked having the top ribbon visible on every page.

Suitability for the Audience

Interactivity was noted by most participants as something that would make the website appropriate for young people. A common suggestion was the use of videos to show the scenarios or to show how to put someone in the recovery position. Participants thought that this would not only be engaging for young people, but it might improve accuracy and clarity of information. Some participants said that some young people have functional literacy issues, so a video would be a better medium for them. Some participants felt that the scenarios section would benefit from being made more engaging, age-appropriate, and fun:

> *Yes, just a little bit engaging or something, you know? Yes, almost like that little video in the… "They're on the street outside the club or something, they've passed out, so you turn them over like this, and then you do this to get help."* [Participant R05, clinical professional]
>
> *You know the text message shown? It might be worth doing another option next to it. You know on the first bit where you could click it?* [Participant RO19, young person]

Wording and tone are crucial for communicating health messages with young people. The youth participants highlighted that they did not want health information to come across as patronizing or too much *from an adult*, although this should be balanced with the trustworthiness and credibility of the information sources. Participants were also mindful of wording that might make them overly worried about alcohol or that tried to imitate the adolescent language. Therefore, information should be delivered with a neutral and nonjudgmental tone. In the main, participants felt that the website embodied this tone. However, some did highlight a few areas that could be perceived as patronizing:

> *I do think this bit, about how not to get a hangover: 'It's easy, do not drink anything' is a bit condescending. If you're saying, 'How to stop a stab wound,' and it's like, 'Easy, just don't get stabbed,' you'd be like, "That doesn't help me."* [Participants RO15, young person]

Generally, participants felt that the website was age appropriate; however, including interactive elements would engage young people for longer.

Discussion

Principal Findings

Our web-based intervention for young people has the potential to be usable and informative for young people, and to address the determinants of behavior (eg, peer effects) and perceptions around alcohol-associated risk. The key requirements for engagement and usability include professional and consistent design, succinct, text-light messages that clarify pathways of risk, interactive and audio-visual components, and trustworthy information. Our findings are consistent with those of studies exploring the usability of alcohol-focused apps for adults and young adults [31,36], which similarly reported the importance ascribed by users to design, interface, and clarity, with low user input (ie, short blocks of text, videos), and credibility and trustworthiness of the information provided. The importance of trustworthiness is also supported by recent systematic reviews, which have highlighted that a *credible source* was one of the BCTs that predicted alcohol consumption [14]. In addition, although we sought user views before this study and regarding an earlier prototype, we nevertheless identified divergent views around content and design, demonstrating, as for others [36], the challenge of developing a digital intervention that is appealing and/or engaging to all.

In part, this is related to the central consideration apparent throughout the interviews, which is the complexity of alcohol use among young people, the multiplicity of situations where it might occur, and the wide range of types and brands of alcoholic drinks. There is a tension here in that participants acknowledge the complexity around alcohol use, while also wanting limited text on the website in favor of images or videos. Balancing nuance, accuracy, and engagement is thus a second key challenge in communicating about harmful alcohol use with young people.

Using the correct tone seemed to be paramount when communicating about alcohol with young people. Participants were mindful of not wanting to be patronized, judged, scared, or told what to do. Although most participants felt the website embodied the correct tone, this further highlights the difficulty in attempting to reduce harmful alcohol drinking while also providing nonjudgmental information about intoxication and alcohol use. As such, the web-based intervention is balancing the dual aims of maintaining the rejection of harmful alcohol behavior before it starts as well as altering it where it exists [37], which is reflected in the website's primary and secondary prevention objectives. In the main, participants thought this balance was achieved by preparing young people for potential situations related to alcohol use as well as delivering facts through neutral language. However, any further enhancements to the website should maintain this consideration of tone, which is informative about the negative consequences of harmful alcohol use while also being nonjudgmental.

There is also a wide range of potential consequences or wider risks associated with alcohol use that young people saw as important for a web-based alcohol intervention. This is noteworthy, since systematic reviews have reported no association between the behavior change technique *information on consequences* and reduced drinking frequency [14,18]. This highlights how perspectives on digital intervention are shaped by individual experiences and thus the importance of personalization. It further reiterates the challenge of communicating information to reduce harms alongside that aimed at reducing consumption.

Many young people indicated that alcohol was embedded within more general concerns, such as what they conceived of as peer influence. This is consistent with previous work that found peers play a central role in young people's drinking behavior and the social contexts within which it occurs [30,38]. The nature of peer influence alters throughout adolescence, with younger adolescents experiencing a greater focus on experimentation, intoxication, and social conformity [29], and may be more susceptible to peer influence [39]. Our findings are consistent with this idea, as participants were interested in sections of the website that addressed peer influence and social situations where they may encounter alcohol use and intoxication. Therefore, health messages related to alcohol use, such as disease and injury, may seem less relevant to younger adolescents, as their more immediate concerns relate to new social situations. Interestingly, young people did not specifically suggest including content regarding the impact of family context, so this was not included. Nevertheless, a parallel qualitative study that explored the views of parents or guardians in relation to adolescent alcohol use (Mitchell S, unpublished data, 2020) will inform the next steps, such as the possibility of a parent-focused section or related resources.

It was apparent that young people had the expectation that websites should be engaging, interactive, and have a contemporary aesthetic. This is unsurprising given how embedded the internet is in people's everyday lives [40], with young people being high users of new technologies. Increases in smartphone availability and affordability mean instant access to the internet for young people in the West [3]. Horvath et al [41] recommend planning adequate budgets for design elements, and teams should be expanded to include experts in learning technologies or web-based intervention development. As many participants noted the difficulty in keeping young people engaged, attention to interactive media such as videos should be considered for delivering health messages, which in turn may need greater expertise and resources. This corroborates previous work with young people who found that web-based health interventions should be presented in an attractive and interactive way to improve the efficacy of the intervention [42]. We included a range of sections and activities in the web-based intervention so that participants would have the opportunity to engage with different components, incorporating the distinct BCTs outlined in the logic model. In the next phase of this work, we will also develop a clear teaching guide and lesson plan, and guide youth group settings to increase the likelihood that young people will engage with all components.

Limitations

We had a small sample in 1 geographical area; thus, the findings cannot necessarily be generalized across geographical regions. The sample also covered a broader age range than the intervention was designed so that older participants could reflect on their recent experience. A larger sample of young people aged between 14 and 15 years would have enabled more extensive analysis around the viewpoints of this age group and differences by age and sex, which was not possible in this study. Interestingly, by including this wider age range, we identified that such a resource could be useful for a broader group. Our sample size was pragmatic and limited by the timescales of our study. However, we found that similar themes were raised by young people and consider our sample size sufficient to enable development and optimization of the prototype website [43]. Finally, we did not gather data regarding participants' alcohol use; thus, we cannot ascertain how alcohol behavior may have shaped perspectives relating to the intervention.

Conclusions

In this study, we have identified the importance of appealing design, low-input interface, interactivity, and credibility in an alcohol-related web-based intervention and the need for involvement of young people at all stages of design and development to ensure that content, tone, usability, and appeal are optimized. Our study also demonstrated the promise of the web-based intervention *Rethink Alcohol*. The next steps will involve optimization and testing of the feasibility of implementing the intervention in schools and youth group settings.

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Authors' Contributions

GM developed the concept for this study, developed the first *Rethink Alcohol* prototype and contributed to data collection, analysis, and interpretation. SM contributed to recruitment, data collection, and analysis. CG, EK, MH, and RC contributed to prototype development and study design. LT analyzed the transcripts and wrote the first draft of the manuscript. All authors read and commented on the manuscript before submission.

Conflicts of Interest

MH has received a payment for unrelated activity from Gilead Sciences Inc, Bristol Myers-Squibb, and Jannsen, UK. CG is involved in the development and testing of the Drink Less app that is unrelated to this work. EK was the lead author of a Cochrane review regarding personalized digital interventions for reducing hazardous and harmful alcohol consumption in community dwelling populations [14]. All other authors have no conflicts to declare.

Multimedia Appendix 1
Screenshots of the intervention website.
[DOCX File , 947 KB - pediatrics_v3i2e19749_app1.docx]

Multimedia Appendix 2
Themes and subthemes used to code the interview transcripts during data analysis.
[DOCX File , 13 KB - pediatrics_v3i2e19749_app2.docx]

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Abbreviations

ALPHA: Advice Leading to Public Health Advancement
BCT: behavior change techniques
CRUK: Cancer Research UK
NIHR: National Institute for Health Research
PDF: Post-Doctoral Fellowship
PSHE: Personal, Social, Health, and Economic
STI: sexually transmitted infection
YPAG: young people advisory group
YPAGNE: young people advisory group north east

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Review

Harnessing Phones to Target Pediatric Populations with Socially Complex Needs: Systematic Review

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Abstract

Background: Mobile and smartphones are owned and accessed by many, making them a potentially optimal delivery mechanism to reach pediatric patients with socially complex needs (ie, pediatric populations who face overlapping adversities).

Objective: To address the specialized needs of youth from such groups, this review synthesized the literature exploring the use of phone-based delivery to access pediatric populations with socially complex needs, targeting mental and behavioral health outcomes. The purpose of this synthesis was to provide recommendations for future research developing phone-based interventions for youth with socially complex needs.

Methods: A trained medical librarian conducted the search strategy in the following databases: PubMed, Scopus, CINAHL, PsycINFO, Cochrane CENTRAL Register of Controlled Trials, Cochrane Database of Systematic Reviews, and Google Scholar. Studies targeting youth with socially complex needs were defined by recruiting samples that were primarily from traditionally underserved populations (ie, sex/gender minorities, racial/ethnic background, low socioeconomic status, rural/remote location, and sexual orientation). A systematic narrative framework was utilized and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines were followed (registration number CRD42020141212).

Results: A total of 14 studies met the inclusion criteria, with 3 depicting the use of phones to complete assessment and tracking goals and 11 to intervene on mental and behavioral health targets.

Conclusions: The literature indicates important directions for future research, including (1) involving diverse and representative teens (ie, the likely users of the interventions), stakeholders, and clinical/research staff; (2) integrating evidence-based therapies with minority-focused theories; (3) harnessing mobile device capabilities; and (4) considering and assessing for potential costs in phones as delivery mechanisms.

Trial Registration: PROSPERO CRD42020141212; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=141212

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KEYWORDS

underserved youth; digital mental health; mHealth; telehealth; health disparities

Introduction

Background

Pediatric populations with socially complex needs are likely to have their behavioral health negatively impacted—from having a lower health status than peers to being less likely to receive appropriate physical and mental health diagnoses [1]. The term “socially complex needs” is used to describe pediatric populations that face overlapping adversities [2]. Such youth may endure adverse childhood experiences, physical symptoms (eg, pain), or be from traditionally underserved populations (eg, low socioeconomic status [SES], belonging to a minority racial/ethnic or gender/sexual minority group, or living in isolation from accessible services [3]). The behavioral health disparities associated with having socially complex needs have lasting detrimental effects, including a higher likelihood of chronic illness in adulthood [4]. For these reasons, repeated calls to promote the behavioral health needs of such pediatric populations have been made [5-10].

The ubiquity of mobile and smartphone access has promoted refrains about the promise of digital mental health tools to overcome access barriers to pediatric behavioral health interventions [11]. While some populations are less likely to adopt computer use and are more likely to lack home broadband access [12], nearly all American adults report owning a mobile phone (96%) [13] and 95% of teens report owning or having access to a smartphone [14]. Therefore, pediatric interventions that harness phones as a delivery mechanism (ie, mobile health [mHealth] and telehealth) may be more likely to successfully access pediatric patients with socially complex needs [13]. However, due to issues such as data plan costs, service lapses, and lower phone literacy, a “digital divide” is occurring that could further perpetuate disparities in the use of phones as a delivery mechanism [15-19]. Indeed, if not appropriately evaluating tools with socially complex populations and adapting designs to fit their user and access needs [20], researchers and clinicians are missing the opportunity to reach pediatric populations through a medium that young people are already using for other purposes (eg, using a smartphone to interact with social media).

Purpose

While more research is critically needed, some work to harness phones as a delivery mechanism specifically for socially complex populations has begun. As the field shifts to adapt such tools to be more inclusive, synthesis of the small but existing literature may be beneficial. Indeed, this synthesis may promote increasing adaptations of such tools for pediatric populations with socially complex needs and avoid potentially superfluous evaluations that would delay deployment to youth in need of support and care. Therefore, to provide recommendations for future research developing inclusive interventions, this study systematically reviewed the literature for multiple criteria. First, a focus on phone-based interventions (mHealth and telehealth) was made. While the field has moved toward a focus on digital health technologies (eg, harnessing mobile or smartphones to deliver monitoring or intervention activities), telehealth interventions that involve calling participants—even on landlines—were included. These criteria were used because interventions using telephone calls to reach youth may still be applicable as smartphones have phone call capabilities. Second, this review focused on mental (eg, mood) and behavioral health targets (eg, physical activity) for pediatric patients with socially complex needs. As any pediatric patient is likely to have socially complex needs (eg, managing symptoms associated with acute or chronic conditions), we operationalized studies that targeted pediatric patients with socially complex needs as those that recruited samples primarily comprising (ie, ≥50%) youth from traditionally underserved populations (eg, low SES, belonging to a minority racial/ethnic or gender/sexual minority group, or living in isolation from accessible services [3]). The synthesis of these findings was used to define (1) uses of phone-based delivery practices; (2) culturally specific tailoring practices; (3) applications of evidence-based skills and grounded theories to inform design; and (4) additional supports that promote comfort, use, or intended intervention outcomes for pediatric populations with socially complex needs.

Methods

Search Strategy

The review was conducted and reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and checklist [21] and was registered prior to data extraction in PROSPERO (registration number CRD42020141212). No limitations were put on the search in terms of language, date of publication, or geographic area. The search strategy included controlled vocabulary (ie, MeSH terms) and keywords in the title or abstract fields. Seven electronic databases were searched, including PubMed, Scopus, CINAHL, PsycINFO, Cochrane CENTRAL Register of Controlled Trials, Cochrane Database of Systematic Reviews, and Google Scholar. The search strategy was conducted collaboratively by the lead author (CS-S) and a trained medical librarian (JW) and the literature search was conducted by a trained medical librarian (JW) in August 2019 (Multimedia Appendix 1).

Inclusion and Exclusion Criteria

For inclusion in the review, studies were required to (1) specifically target a pediatric population with socially complex needs (as noted above, this was operationalized by the majority [>50%] of the sample belonging to an underserved group [eg, minority population, low SES, rural geographical location] [3]); (2) utilize a phone (ie, smartphone, cellphone, landline, SMS text messages, push notifications, gathering passive data, or have a user access an app[s]) as a means of targeting youth (phones could be used as the sole delivery mechanism or as part of a multimethod intervention delivery); (3) report outcomes related to mood (eg, depression, sadness, low mood), anxiety/stress, or wellness (eg, exercise, diet, sleep, treatment adherence); (4) include samples that were at least 50% under the age of 18; and (5) be written in English. Technical validation papers reporting on the development of digital mental health interventions, conference abstracts, review papers, and samples fewer than 20 were excluded.

Study Selection

Literature search results were uploaded into Covidence, a not-for-profit, online systematic review service partnered with Cochrane [22]. From the initial search results, all titles and abstracts were independently screened by 2 reviewers against the inclusion criteria. Following this, full-text articles were also reviewed by 2 independent reviewers. Any discrepancies about inclusion at either stage were resolved through consensus with a third reviewer.

Data Extraction

Reviewer teams (CS-S, LP, DB, MB, JD, CO, EW) extracted data (eg, sample characteristics, use of phone, primary outcomes) independently and in duplicate from each eligible study using an online extraction form designed by the lead author (CS-S) using Google Forms. Discrepancies were, again, resolved through consensus.

Quality Assessment

The Cochrane Collaboration's tool for assessing risk of bias in randomized trials was used to assess the risk of bias for selection, performance, detection, attrition, and reporting [23]. Specifically, each study that was included in the final review was independently rated in duplicate for each form of bias.

Data Synthesis

Because of the variability in outcome measures and methodologies, a meta-analytic approach was deemed inappropriate for the current review. Alternatively, a systematic narrative framework was utilized, with results classified under “Tracking and Assessment” or “Intervention.” To best inform the design of future interventions for pediatric populations with socially complex needs delivered through phones, the systematic narrative synthesis included *population-specific tailoring*, *evidence-based skills and theories* (interventions only), *use of phones for delivery*, and *additional support*. These categories were selected prior to data collection as they would provide key insights from the literature into development decisions made for specific user needs relating to pediatric populations with socially complex needs. Finally, to contextualize the findings, *study characteristics*, *primary outcomes*, and *usage and acceptability* were also included.

Results

Included Studies

Following the removal of duplicates identified by Covidence, 4626 titles and abstracts were independently reviewed in duplicate by 2 reviewers. A total of 69 full-text articles were reviewed in duplicate for inclusion, with 14 articles selected for data extraction. See Figure 1 for the PRISMA flow diagram. Of the 14 studies, 3 focused on tracking and assessment and 11 were intervention based. Findings from the 3 *Tracking and Assessment* studies will be discussed, followed by findings from the 11 *Intervention* studies, and finally, the outcomes of the quality of all included studies will be presented.

Figure 1. PRISMA flow diagram for study inclusion. aAdapted from “Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement,” by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, and The PRISMA Group, 2009, PLoS Med. 6(7), e1000097.

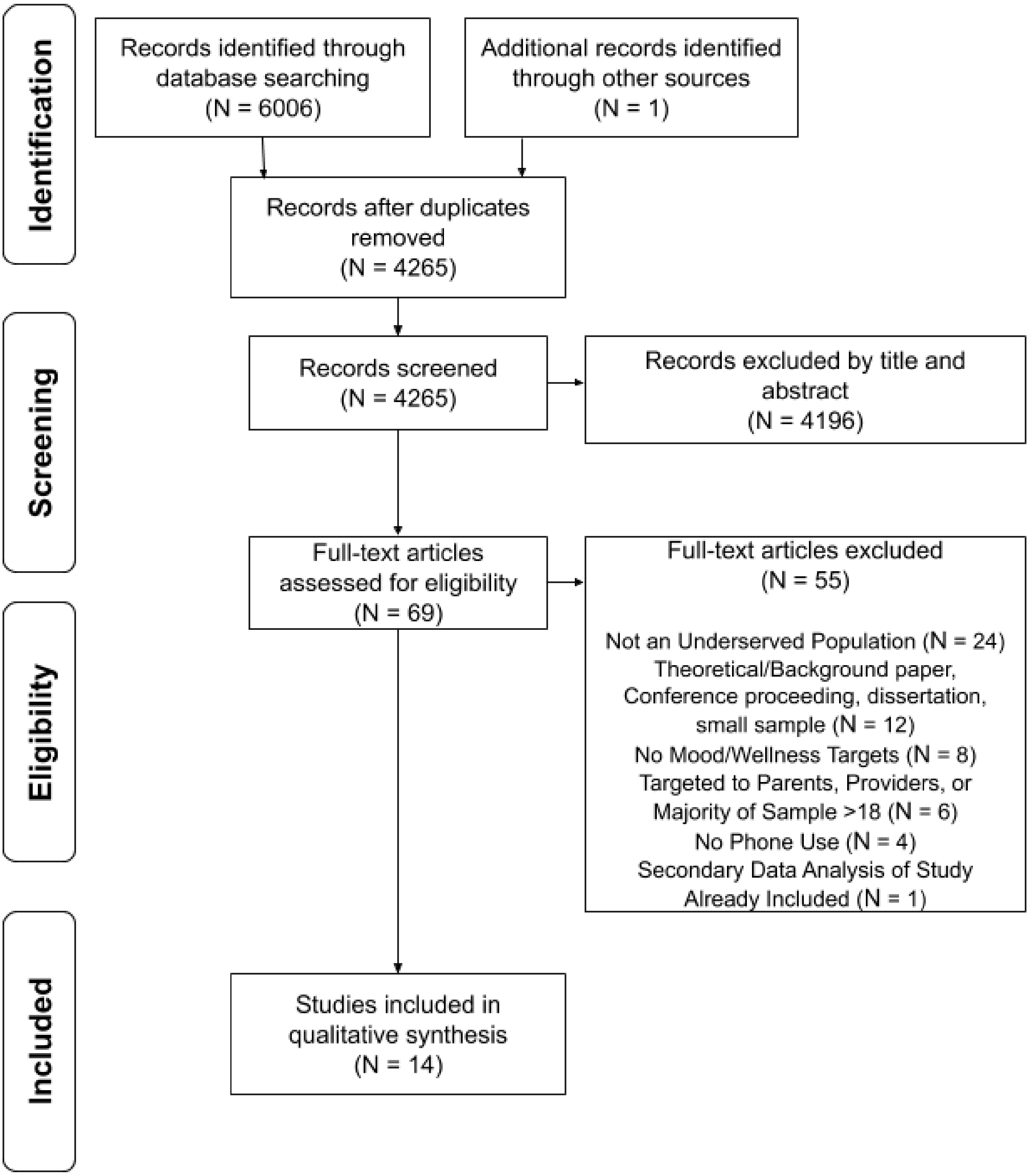

Table 1. Study characteristics.

Classification and authors (year) [Reference]	Target condition, population/outcome	Name	Modality	Additional support	N (Intervention)	Age, % Female
Tracking and Assessment						
Bakshi et al (2017) [18]	SCD[a]/Pain symptoms management tracking	Not applicable	SMS text message, Web EMA[b]	PRN[c] (A)[d]	20	12-22, 75
Jacob et al (2012) [19]	SCD/Pain symptoms management tracking	Wireless Pain Intervention Program	Mobile Web Page	PRN (A)	67	10-17, 54
Odgers and Russell (2017) [20]	At-risk, low SES[e]/violence exposure + behavioral health	miLife	Mobile EMA	No	151	11-15, 48
Intervention						
DiClemente et al (2014) [21]	African American teen girls/Safe sex behaviors	HORIZONS	Phone call[f]	Yes	701 (342)	14-20, 100
Leonard et al (2018) [22]	Homeless moms/Emotion regulation	Calm Mom	App[f]	Yes + A	49	13-21, 100
Nollen et al (2014) [23]	Low SES, minority Girls/Obesity-related behaviors	NR[g]	App[f]	No	51 (26)	9-14, 100
Perry et al (2017) [24]	Low SES, minority teens/Asthma	NR	App[f]	No (A)	34 (17)	14-16, 38
Reid et al (2011) [25]	Rural primary care/emotional self-awareness, mood, anxiety	mobiletype	App, EMA[f]	PRN	114 (68)	14-24, 72
Rokicki and Fink (2017) [26]	At-risk teen girls/Safe sex behavior knowledge	NR	SMS text message[f]	No (A)	498 (205)	14-24, 100
Schatz et al (2015) [27]	SCD/Pain coping	NR	App, phone call	Yes	46 (23)	8-21, 59
Seid et al (2011) [28]	Low SES, minority teens/Asthma	NR	SMS text message[f]	Yes + A	26 (14)	12-18, 69
Smith et al (2014) [29]	Low SES teen boys/Obesity-related behaviors	ATLAS	App[f]	Yes	361 (181)	12-14, 0
Thompson et al (2016) [30]	Minority teens/Obesity-related behaviors	NR	SMS text message[f]	Yes + A	160 (120)	14-17, 52
Ybarra et al (2017) [31]	Sexual minority teen boys/Safe Sex behavior, HIV prevention	Guy2Guy	SMS text message[f]	Yes + A	320 (150)	14-18, 0

[a] SCD: sickle cell disease.

[b] EMA: ecological momentary assessment.

[c] PRN: as needed.

[d] A: automated support.

[e] SES: socioeconomic status.

[f] Explicitly detailed use of population-specific tailored messaging or design practices.

[g] NR: not reported.

Tracking and Assessment

Study Characteristics

Three studies targeted mood, anxiety, or wellness outcomes for socially complex pediatric populations through tracking and assessment. Specifically, 2 studies focused on pain tracking for African American youth with sickle cell disease (SCD) [24,25]. The third study focused on violence exposure and psychosocial factors for adolescents from low SES neighborhoods who also presented with at least three parent-reported risk factors (ie, behavioral difficulties, inattention and hyperactivity, early initiation of substance use, or having a parent with a substance misuse issue) [26]. All of the samples were recruited from the United States of America and ranged in size from 20 to 151. Two samples were primarily female [24,25] and 1 was minority female [26]. See Table 1 for study characteristics.

Population-Specific Tailoring

Of the 3 studies, only Bakshi et al [24] directly reported or cited prior work discussing the use of tailoring the study to a particular population's needs. Specifically, cognitive interviewing techniques were used to ensure content validity of the messaging (eg, removing fatigue from assessment queries, as it not associated with experience of patients with SCD), semistructured interviews were conducted for feedback on content and design layout (eg, change the workflow so as to not assess the impact of pain on schoolwork if there were no assignments that day), and user reviews following site creation (eg, demonstrated acceptability) were completed with adolescents and young adults with SCD for a web-based multidimensional pain diary [38]. In addition, participants who might be unable to use/access the web-based platform had the option to transmit pain reports via SMS text message [24].

Use of Phones for Delivery

The 3 studies utilized mobile phones or smartphones in some way to deliver their assessment. Bakshi et al [24] employed a web-based ecological momentary assessment (EMA) platform for their pain intensity diary; however, they included SMS text messaging of pain reports to overcome barriers to accessing the webpage. While Jacob et al [25] also utilized a web-based diary system, they provided smartphones with wireless packages to all participants to enter data. Similarly, Odgers and Russell [26] provided smartphones preprogrammed to alert three times within each participant's schedule.

Additional Support

Support beyond the described use of phones was included in the methodology of 2 studies. First, Bakshi et al [24] described having study staff contact participants with SCD if a pain report surpassed a predetermined rating threshold. This support was intended to promote pain management assistance from a provider or hospital [24]. Second, Jacob et al [25] reported having (1) participants with SCD attend an in-person information session on utilizing smartphones to access the e-Diary; (2) an advanced practice registered nurse monitor symptoms and contact participants if reports reached clinical elevations; (3) unlimited SMS text message and phone call support options for participants to contact the advanced practice registered nurse; and (4) technology support as needed.

Primary Outcomes

The primary outcome for the studies tracking SCD symptoms was pain. However, the 2 studies reported these findings differently. Bakshi et al [24] reported that their participants with SCD endorsed having pain on the majority of days (76.2%); 30% of participants had all of their entries indicating pain, whereas another 30% primarily denied having pain for most of the time. Jacob et al [25] reported that over half of all diary entries included pain (55%) and that their participants with SCD had a mean pain rating of 4.1 (SD 2.2; range 1-10, with 10 being highest), with no evidence to suggest differences from morning and evening pain, nor by age (10-13 vs 14-17 years). Odgers and Russell [26] identified that 75% of their sample was exposed to violence on at least one day, and reported depressive symptoms about a quarter of the time, anger or irritability nearly 15% of the time, conduct problems about 7% of the time, and health-risk behaviors about 13% of the time. In addition, anger, depression, and conduct problems were more likely to be reported on violence-exposed days and depressive symptoms were more common on days following violence exposure [26]. See Multimedia Appendix 2 for study outcome details.

Usage and Acceptability

Usage and acceptability reports were also variable across studies. EMA was completed the majority of time for Bakshi et al [24], with more than 85% of study days associated with 2 or more completed EMAs. During focus groups, participants reported positive experiences and improved pain communication with their providers [24]. The other two studies indicated total number of reports completed (9216 entries [25] and >13,000 assessments and 4329 person days [26]) without any description of participant acceptability. See Multimedia Appendix 2 for usage and acceptability outcomes.

Intervention

Study Characteristics

Eleven studies reported interventions targeting mood, anxiety, or wellness outcomes for pediatric populations with socially complex needs. Specifically, interventions targeted (1) sexual risk behaviors in (i) African American adolescent females [27], (ii) at-risk adolescent females from a remote area in West Africa (Ghana) [32], and (iii) sexual minority adolescent males [37]; (2) obesity-related behaviors in (i) racial/ethnic minority adolescent females from low SES homes [29], (ii) adolescent males from low SES homes [35], and (iii) adolescents from diverse racial/ethnic backgrounds [36]; (3) asthma adherence in racial/ethnic minority adolescents from low SES homes [30,34]; (4) emotion regulation in homeless adolescent mothers [28]; (5) emotional self-awareness and mood symptoms in adolescents and young adults treated in rural primary care settings [31]; and (6) pain coping in racial/ethnic minority adolescents with SCD [33]. All samples were American, with the exception of 2 from Australia [31,35] and 1 from Ghana [32]. Samples ranged in size from 26 to 701, and nearly half consisted entirely of one sex [28,30–32,36,37]. See Table 1 for study characteristics.

Population-Specific Tailoring

Four studies explicitly described tailoring of the intervention to the targeted population. DiClemente and colleagues [27] utilized health educators matched by race and sex to the participants for the in-person session (ie, African American females) and described specifically tailoring the telephone counseling strategies to address sexual risk factors as prioritized by the participants (eg, a partner declining to wear a condom). Using participants themselves to tailor the intervention, Seid and colleagues [34] reported that participants created their own messages that would be sent as SMS text message during the intervention period. Examples included behavioral cues (eg, “Take your meds and go exercise.”), motivational messages based on personal reasons for change (eg, “Don’t quit. You can do it.”), and general queries (eg, “Doing okay with your asthma? If not, call…”). Thompson et al [36] depicted both in text and through reference of an earlier work [39] an iterative approach to developing 84 SMS text message prompts (12 goal prompts, 72 promoting psychological needs; equally grounded in autonomy, competence, and relatedness) with 160 adolescents who were primarily racial/ethnic minorities. Examples included SMS text messages grounded in autonomy (eg, “You’re in charge! Make the choice to meet your step goal today!”), competence (eg, “You can meet your step goal; just keep steppin’!”), and relatedness (eg, “Meeting your step goal shows you have what it takes to be successful!) [36]. Finally, Ybarra and colleagues [37] tailored messages based on sexual experience. For example, sexually experienced teens received an SMS text message such as “When you’re in a healthy relationship and start having sex…,” whereas sexually inexperienced teens would view: “When you have sex…” [37].

Three studies cited previous work depicting iterative design input from potential end users. While Leonard et al [28] reported qualitative feedback from their participants about their system, they cited a prior pilot conducted with 4 African American or Latinx adolescent mothers from low SES families at high risk for school dropout. Findings indicated participants’ desire to make the sensor bands that measured electrodermal activity (a physiological stress indicator) more comfortable and fashionable in appearance [40]. Nollen et al [29] cited previous work that formed a community advisory board (CAB) of adolescent girls, who were primarily racial/ethnic minorities, to provide feedback on the use of the technology platform and to test 2 iterations of prototypes of the intervention. The CAB requested more reminders, accountability monitoring, and free music as an incentive for use; these were incorporated in later iterations of the design [41]. Reid and colleagues [31] cited previous focus groups with high-school students to tailor their app question prompt language (eg, make it less repetitive) [42].

Four studies provided vague or no descriptions of tailoring the intervention to a specific population. While Perry et al [30] provided limited detail on tailoring (eg, colorful graphics), they described seeking input from community stakeholders (teens with asthma and their parents). Rokicki and Fink [32] reported integrating feedback from adolescent focus groups and health providers to design the intervention language; however, no examples were provided. Smith and colleagues [35] described using tailored informational and motivational SMS text messages that were pushed to participants without providing details of this tailoring. Finally, to the best of our knowledge, Schatz and colleagues [33] did not describe tailoring in any way.

Evidence-Based Skills and Theories

The included studies reported the use of evidence-based skills and grounding in multiple theories. The most common evidence-based treatments were cognitive behavioral therapy (CBT) [28,33], skills related to CBT (eg, behavior modification through goal setting and self-monitoring) [29,41], mindfulness [28], problem-solving skills training [34], and motivational interviewing [34]. Disease-specific interventions and models of change were also noted for asthma (asthma action plans) [30] and HIV (Information-Motivation-Behavior Model of HIV) [37]. Finally, self-determination theory [35,36], social cognitive theory [27,35], and the theory of gender and power [27] were used to inform several interventions. These theories were not necessarily used in isolation. For example, DiClemente and colleagues [27] grounded their intervention (HORIZONS) in both evidence-based treatment [43,44] and minority-based theory [45,46].

Use of Phones for Delivery

Consistent with the inclusion criteria, all studies used phones for some means of intervention delivery. Included in 5 studies, smartphone apps were the most commonly reported phone-based delivery mechanism [29-31,33,35], followed by the use of SMS text messaging, in 4 studies [32,34,36,37]. A total of 5 studies described providing some or all of their participants with a mobile phone or smartphone for the duration of the study [31,35–38]; 1 study did not clarify whether participants used their own devices [35]. Two studies required that participants have their own mobile phone with unlimited SMS text message/data plans [36,37]. Finally, DiClemente and colleagues [27] described the delivery of brief, tailored telephone-delivered counselling sessions following a single, in-person training session.

Additional Support

With one exception [29], all studies included some form of additional support to participants. Five studies included at least one in-person therapy or skills training session [27,28,33-35], with one additional study including training for teachers who would be interacting with participants throughout the intervention [35]. Four studies utilized automated support in the form of SMS text messages or reminders [29,34–36]. Three studies provided remote support with telephone-delivered counseling or check-ins [27,33] or being paired with a “text buddy”—another participant matched on sexual experience (ie, experienced or inexperienced) within 1 time zone but at least 500 mi away [37]. Finally, 3 studies reported using “as needed” remote human support via telephone calls [31,33] or SMS text messaging [36], which was activated when there were concerns for safety or poor adherence.

Primary Outcomes

The primary outcome measures and results varied considerably across the 11 intervention studies. Three studies reported using intent-to-treat analyses [27,31,37]; 2 studies reported nonsignificant primary outcomes [36,37] and 2 reported changes in knowledge or behaviors without noting significance values [28,32]. For pediatric condition-specific interventions, those with (1) uncontrolled asthma had improved asthma control test scores following use of the asthma action plan app (P=.04) [30]; (2) asthma that had received tailored SMS text messages had medium to large effect size changes in asthma symptoms and health-related quality of life [34]; and (3) SCD demonstrated a group (CBT training and app vs waitlist control) × time interaction for coping attempts (P=.03) [33]. For obesity-related behavior interventions reporting significant findings, the use of an app targeting obesity-related behaviors in racial/ethnic minority adolescent females from low SES homes was associated with less sweetened beverage consumption (*P*=.01) [29], whereas use of an app with a school-based program was related to changes in screen time (*P*=.03), lowered sweetened beverage consumption (*P*=.01), increased muscular fitness (*P*=.04), and increased resistance training skills (*P*=.001) [35]. To target sexual risk behaviors in adolescent females, those receiving telephone counseling were less likely to have a chlamydial infection (*P*=.02) or report having sex while high (*P*<.001), and more likely to use a condom (*P*=.04) [27]. Finally, in an app targeting emotional self-awareness and mood symptoms in adolescents and young adults treated in rural primary care settings, there was a group (monitoring mood symptoms vs daily activity monitoring) × time interaction effect for emotional self-awareness (*P*=.048) and main effects for depression and anxiety symptoms (*P*<.02 for both) [31]. See Multimedia Appendix 2 for primary outcomes.

Usage and Acceptability

One study did not report usage data [34] and 5 did not report acceptability [28–30,37,38]. Usage was reported in variable ways, including percentage of sample that used or reported using the SMS text messages/app [32,35,36], percentage of completed entries [33], average daily SMS text messages [37], total number of calls [27], duration of app use [28], percentage of days used [29], and frequency (eg, days per week or times per week) [30]. Three studies reported a numeric rating for acceptability or satisfaction with the intervention [28,29,36]. Two studies provided the percentages of their sample who agreed with statements such as “I would recommend the app to a friend with asthma” [30,35]; one study described participants as finding the intervention to be “appealing” [34]. See Multimedia Appendix 2 for usage and acceptability outcomes.

Quality of Studies

The included studies ranged from tracking and assessment to interventions, indicating that different methodologies were anticipated. Indeed, the 3 tracking and assessment studies, by the very nature of their purpose, were deemed high risk for selection, performance, and detection biases (Multimedia Appendix 3) [23]. Further, allocation concealment as well as performance and detection biases were variable, likely due to the nature of frequently involving technological delivery mechanisms (eg, knowing which arm a participant is assigned because they have access to an app or not). Attrition bias was high for 1 tracking and assessment study [24], but low (11/14, 79%) or unclear (2/14, 14%) for all other studies. Finally, all studies had a low reporting bias.

Discussion

Principal Findings

This study synthesized the literature on the use of phones (ie, mHealth and telehealth) as a mental and behavioral health delivery mechanism for pediatric populations with socially complex needs. There was high variability in methodological approaches and reporting of data, negating the possibility of a meta-analytic approach to this systematic review. The studies that met the inclusion criteria were primarily intervention based and occurred mainly in 2005-2007 (we assumed that these studies primarily used landline calls) [27]. Samples included targeting typically underserved populations by gender [28–32,36], racial/ethnic background [24,25,28,33–35], low SES status [26,31,32,34–36], rural/remote location [31,32], and sexual orientation [37]. Usage and acceptability of the delivery mechanisms were inconsistently reported and therefore difficult to generalize. Finally, given the nature of the included studies, risk of bias to issues such as blinding was generally high.

The purpose of this synthesis of the literature was to provide recommendations for future research developing phone-based interventions for youth with socially complex needs. The following sections will therefore be used to discuss implications of the current findings for the development of future interventions targeting such pediatric groups. Specifically, we discuss (1) uses of phone-based delivery practices, (2) culturally specific tailoring practices, (3) applications of evidence-based skills and grounded theories to inform design, and (4) additional supports that promote comfort, use, or intended intervention outcomes for pediatric populations with socially complex needs.

Phone-Based Delivery

Given the ubiquity of mobile phones and smartphones [14], the use of these devices to reach socially complex pediatric populations has great merit. This focus on mobile devices stands in contrast to previous efforts to deliver evidence-based treatments via computer-based platforms [47,48] and may more accurately reflect the device and broadband access of underserved communities [12]. Further, phones are now equipped with multiple access capabilities, such as the ability to provide context sensing and just-in-time interventions (ie, acting when youth are most likely to be in need of in-the-moment intervention) [49,50]. It is possible that more interventions for socially complex pediatric populations will be entirely encompassed within mobile platforms, including multimethod (eg, context sensing, calls, SMS text messages, and an app), just-in-time, or stepped care designs (eg, early nonresponders step up care from SMS text messaging only to SMS text messaging + app, to SMS text messaging + app + telephone-administered CBT).

Apps and SMS text messaging were the most commonly employed method to access youth. This is consistent with current usage trends, such that youth are more likely to use SMS text messaging or social media to communicate than phone calls [51]. While apps are numerous and widely accessible, adoption is often poor [52] and there appear to be gaps in coverage across development (eg, apps aimed primarily at children or adults, but fewer for teens). Further, pediatric clinical-scientists are unlikely to develop, evaluate, and disseminate apps in pace with industry-driven apps [53], making the development of future apps targeted specifically for unique pediatric conditions or samples less feasible without industry support. Therefore, despite apps and SMS text messaging both being the most frequently used within the studies included in this review, we venture that there may be benefit in also focusing on using SMS text messages to assess and intervene with pediatric samples with socially complex needs. Indeed, SMS text messaging interventions are (1) low cost (for interventionists; please see below about discussion of potential costs for users); (2) consistent with technology practices identified within several underserved population groups [14]; (3) not as easily ignored as push notifications and do not require a user to open a specific or potentially "identifiable" app (eg, a teen might fear that a specific app would be recognized by a peer for treating depression); (4) and associated with improvements in behavioral health behaviors for general pediatric and pediatric populations from underserved communities [16,54–56]. While the future of phone-based delivery of pediatric interventions may be multifaceted, apps and SMS text messaging appeared frequently in the current literature. We posit that SMS text messaging may be a particularly viable option for engaging populations with socially complex needs in pediatric assessments and interventions.

Relevant to the use of phones, potential costs associated with the use of phones as mental and behavioral health delivery mechanisms are also worth noting. Indeed, this consideration is particularly crucial in trying to access certain socially complex populations who are more likely to be impacted by lapses in service or burdened by the cost of data packages/SMS text messaging plans [15,18]. Several studies provided phones or data/SMS text messaging plans to participants, whereas others required that participants already own a smartphone with unlimited data/SMS text messaging plans. Previous work has already described design recommendations to avoid hidden costs to users (eg, data downloads when connected to Wi-Fi) [54]. However, ongoing assessments relating to the costs or burdens of mHealth, telehealth, and other use of future digital mental health tools should be conducted with representative pediatric populations and their families.

Culturally Specific Tailoring

Informing design with the feedback and preferences of likely end users is an integral aspect of user-centered design practices [55]. Cultural tailoring should therefore not be a unique practice. However, as there is limited literature targeting pediatric patients with socially complex needs (ie, only 14 studies meeting inclusion criteria for this review), such tailoring has rare representation. Involvement of representative end users in the design process was described in varying detail across studies. Given the paucity of direction for designing for specialty populations, papers specific to development (eg, [40–42]) or more explicit depictions of culturally specific tailoring are critically necessary for future publications.

Involving representative end users (eg, pediatric populations with socially complex needs) in design decisions may be achieved through multiple means. For example, the current literature detailed the use of semistructured individual interviews, focus groups, membership in a CAB, and stakeholder involvement. Recruiting youth to participate in such activities likely requires multimethod strategies, including flyers or targeted electronic chart messaging from pediatric primary care, school-based health centers, or specialty clinics. Engaging community organizations in partnership to engage youth will also increase the likelihood of receiving input from populations who have been historically less involved in research. Examples from the current literature depicted recruitment through specialty clinics (eg, SCD treatment site) or community settings to aid in tailoring messages or determining workflow of the interventions. Message tailoring was achieved through engaging representative groups, using messages authored by individuals for themselves [34], or by altering language based on membership to a given category (eg, sexually experienced vs inexperienced) [37]. As noted above, the authors posit that SMS text messaging stands as a viable means to engage underserved pediatric populations in assessment and interventions. Language utilized in such messages must be appropriate for the youth's needs, requiring brevity, clarity, minimal jargon, inclusive language choices, and the avoidance of a condescending tone—particularly for adolescent users [20,56,57]. It seems unlikely that such goals for language could be achieved without the direct input of the populations who would be using the tools. Indeed, as intervention design is inherently led by adults, the authors venture that beyond user-centered design practices, all pediatric interventions should have some form of input from youth. Regarding workflow, flexibility appears to be critical. Indeed, welcoming input from potential users about what they view as their top priorities and needs likely promotes engagement and usability.

Applications of Evidence-Based Skills and Grounded Theories

Also integral to the methodologies of interventions targeting pediatric populations with socially complex needs is grounding the design in evidence-based treatments. Skills grounded in CBT were most commonly employed to achieve the intended behavioral change in the studies meeting inclusion criteria. However, theories relating to minority populations (eg, promoting power, equity) were also used to guide the interventions. As members of underserved populations tend to have intersectional identities (eg, individual identification with minority status in sex/gender [female], ethnicity [Latinx], and SES [low SES]), grounding in theory likely also requires an intersectional approach. For example, in targeting sexual risk behaviors in African American adolescent females, the HORIZONS intervention was grounded in multiple theories, incorporating both an evidence-based treatment [43,44] and a minority-based theory [45,46]. Future interventions for underserved pediatric populations will likely benefit from similar integrative models of theory.

Additional Supports

Additional supports, whether automated, human, or both, also appear to be important for interventions targeting pediatric populations with socially complex needs. The potential for automated responses promotes the scalability of interventions for specific population targets. However, relating to the specialty needs of varying pediatric populations who may also be from underrepresented groups, the ability to have support as needed or ongoing human support may also be important. Fortunately, the incorporation of human support further opens up the possibility of increased diversity in the workforce that designs and deploys such interventions. Indeed, the US Department of Health and Human Services' Office of Minority Health argues that one way to improve health disparities is by increasing clinical workforce diversity [58]. Ideally, human support staff (eg, health educators, clinicians, researchers) should therefore include demographic membership that is in some way representative of the patients being served. For example, DiClemente and colleagues [27] ensured that all in-person contacts (ie, recruitment, health education sessions) were staffed by professionals matched by gender (female) and race (African American) to the participants [27]. Such inclusive hiring and collaborative processes likely enhance patient engagement and further promote cultural-tailoring practices highlighted above.

Limitations

This systematic review should be interpreted in light of specific limitations. First, the studies meeting inclusion criteria were incredibly variable in their methodologies and reporting strategies. This variability precluded a meta-analytic data approach to data synthesis and we were hesitant to overinterpret outcomes and usage patterns. Related to the variability in the studies, the search for research about “pediatric populations with socially complex needs” comprises a broad group. The current findings should be interpreted in terms of broad application to these pediatric populations. Second, the inclusion criteria for this systematic review led to the exclusion of more broad applications of mHealth and telehealth interventions for pediatric populations (eg, samples that included primarily majority population participants). It is unclear how larger reviews of the literature for pediatric populations may generalize to the populations targeted in this review, and vice versa [59]. Third, the included studies were conducted in the context of specific research trials. It is unclear how the findings generalize to open deployment and if there are specialty concerns for specific underserved groups (eg, regional differences). Further, a number of studies did not report postintervention follow-up data. It is therefore difficult to identify potential long-term impacts of the interventions. Finally, and as previously noted, we were also limited in our ability to synthesize cultural-tailoring practices, as multiple included studies did not explicitly report these methodologies. Indeed, future detailed depictions of design practices identified with and for specific underserved pediatric populations are needed going forward—in both primary outcome reports and reviews.

Conclusions

Repeated calls have been made to better target the behavioral health needs of pediatric patients with socially complex needs. Mobile devices are often owned and utilized, and therefore may be an optimal delivery mechanism to access youth from such groups. Given the need to focus such interventions to the specialized needs of socially complex youth, this study systematically reviewed the literature of phone-based interventions (mHealth and telehealth) aimed at mental and behavioral health targets for pediatric populations. The synthesis highlighted the importance and potential opportunities of (1) the involvement of representative end users, stakeholders, and clinical/research staff; (2) integration of evidence-based therapies with minority-focused theories; (3) harnessing the capabilities of mobile devices, including SMS text messaging; and (4) considering and assessing for potential costs related to phones as delivery mechanisms. Future research should promote such practices and explicitly detail population-specific tailoring, usage, and acceptability of interventions delivered via mobile devices.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Search strategy and terms.
[DOCX File , 14 KB - pediatrics_v3i2e19269_app1.docx]

Multimedia Appendix 2
Study outcomes.
[DOCX File , 20 KB - pediatrics_v3i2e19269_app2.docx]

Multimedia Appendix 3
Study risk of bias.

[DOCX File , 17 KB - pediatrics_v3i2e19269_app3.docx]

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Abbreviations

CAB: community advisory board
CBT: cognitive behavioral therapy
EMA: ecological momentary assessment
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SCD: sickle cell disease
SES: socioeconomic status

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Review

eHealth and mHealth Psychosocial Interventions for Youths With Chronic Illnesses: Systematic Review

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Abstract

Background: An estimated 12.8% of children and adolescents experience chronic health conditions that lead to poor quality of life, adjustment and coping issues, and concurrent mental health problems. Digital health deployment of psychosocial interventions to support youth with chronic illness has become increasingly popular with the advent of the technological advances in the digital age.

Objective: Our objectives were to systematically review published efficacy studies of eHealth and mHealth (mobile health) psychosocial interventions for youths with chronic illnesses and review intervention theory and treatment components.

Methods: PubMed, Embase, Web of Science, PsycInfo, and Cochrane Database of Systematic Reviews were searched for studies published from 2008 to 2019 of eHealth and mHealth psychosocial interventions designed for children and adolescents with chronic illnesses in which efficacy outcomes were reported. We excluded studies of interventions for caregivers, healthy youth, disease and medication management, and telehealth interventions that function solely as a platform to connect patients to providers via phone, text, or videoconference.

Results: We screened 2551 articles and 133 relevant full-text articles. Sixteen efficacy studies with psychosocial and health outcomes representing 12 unique interventions met the inclusion criteria. Of the included studies, 12 were randomized controlled trials and 4 were prospective cohort studies with no comparison group. Most interventions were based in cognitive behavioral theory and designed as eHealth interventions; only 2 were designed as mHealth interventions. All but 2 interventions provided access to support staff via text, phone, email, or discussion forums. The significant heterogeneity in intervention content, intervention structure, medical diagnoses, and outcomes precluded meta-analysis. For example, measurement time points ranged from immediately postcompletion of the mHealth program to 18 months later, and we identified 39 unique outcomes of interest. The majority of included studies (11/16, 69%) reported significant changes in measured health and/or psychosocial posttreatment outcomes, with small to large effect sizes.

Conclusions: Although the available literature on the efficacy of eHealth and mHealth psychosocial interventions for youth with chronic illnesses is limited, preliminary research suggests some evidence of positive treatment responses. Future studies should continue to evaluate whether digital health platforms may be a viable alternative model of delivery to traditional face-to-face approaches.

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KEYWORDS

pediatrics; chronic illness; mHealth; eHealth; psychosocial interventions; mental health

Introduction

An increasing number of youths (ie, children and adolescents aged 18 years and younger) are diagnosed with a chronic condition in the United States, with an estimated prevalence rate of 12.8% [1-3]. Chronic illness in childhood negatively impacts quality of life [4,5]. Chronic health conditions can lead to emotional challenges and heighten coping difficulties [6]. Up to 60% of children with a chronic illness have at least one co-occurring psychological disorder [7], compared with 10% to 20% of the general pediatric population [8]. Across illness type, stressors associated with chronic disease are vastly similar. Burdens to these populations include treatment-related stress, changes to daily life and routines, and uncertainty about the future [7,9].

Face-to-face psychosocial interventions such as cognitive behavioral therapy are designed to teach and bolster coping skills and improve psychological adjustment [10]. Such interventions have been developed for various illness populations to improve psychosocial outcomes and quality of life [11]. However, barriers to in-person treatment include limited availability of and access to psychosocial clinicians and high costs of treatment [12,13]. A majority of youths screened in school and primary care settings with elevated mental health symptoms do not follow-up with referrals to mental health clinicians, especially those who are racial/ethnic minorities, have public insurance, or come from low-income households [14]. Additionally, there are workforce shortages in proportion to demand and need, with wait times for psychiatric care appointments exceeding that of pediatricians [15]. A potential solution is leveraging technological advances and digital media to deploy behavioral health interventions on a larger scale. Internet-based interventions (otherwise known as eHealth interventions) confer the advantages of instant availability, anonymity, self-pacing, the ability to reach patients in remote areas, and cost-effectiveness due to reduced personnel and infrastructure requirements [16,17].

Internet-based interventions may be particularly appealing to younger generations who are digital natives accustomed to interacting on smartphones and the internet [16-18]. The internet serves as a primary means of health-related and mental health–related information-seeking and communication for youths [19,20]. Additionally, young people endorse reluctance to seek psychological services due to social stigma, discomfort discussing personal problems, and a preference for self-help [16,17,19,21]. Thus, there has been a rapid growth in the use of eHealth platforms to deploy skills-based behavioral health programs for youths. Moreover, in recent years with the increased use of smartphones there has been a corresponding increase in mobile health (mHealth) apps for symptom self-management on smartphone devices [22,23].

Previous systematic reviews have examined digital interventions in pediatric populations for disease self-management and alleviation of mental health symptoms. Examples include remote management of pediatric chronic pain [24] and technological interventions for asthma self-management in children and adolescents [25-27]. Other reviews have focused on digital health interventions for youth mental health problems [28,29] and internet-based cognitive behavioral therapy for children and adolescents [17,30]. The literature has addressed the benefits of eHealth interventions for anxiety and depression [31], technological tools for disease self-management [32], and technology-based family interventions for improving family functioning [33].

To our knowledge, no existing systematic review has been conducted to critically review the literature on eHealth and mHealth psychosocial interventions for youths with chronic illnesses. Previous reviews in this topic area have focused more narrowly on specific chronic conditions, constellations of mental health symptoms, or types of psychotherapy. Our study objectives were to systematically review the efficacy of eHealth and mHealth psychosocial interventions for youths with chronic illnesses and review underlying intervention theory and treatment components.

Methods

Literature Search

The search was executed by a research librarian in five databases for articles published from 2008 to 2019: PubMed/MEDLINE, Embase, Web of Science, PsycINFO, and Cochrane Database of Systematic Reviews. We used keywords and Boolean operators [34] to identify original articles on eHealth and mHealth psychosocial interventions designed for youths or young adults with chronic illnesses. Inclusion criteria were (1) available in English; (2) published in peer-reviewed journal; (3) experimental, quasi-experimental, and observational studies in which efficacy outcome(s) were reported; (4) eHealth or mHealth psychosocial interventions (with technology as the primary mode of content delivery, either entirely self-guided or human-assisted); and (5) designed for children and adolescents aged 18 years and younger with chronic disease (ie, a long-term medical condition lasting 3 months or longer [35]).

The original primary search strategy with generic chronic illness search terms is shown in Multimedia Appendix 1. Cancer is a specific condition of interest for our research group for which we were aware of existing digital intervention literature. Based on our primary search strategy, the authors identified several known published studies on digital interventions related to 10 specific chronic illnesses. To ensure all relevant articles were captured, a supplemental search strategy related to the specific chronic illnesses identified was then conducted to generate systematic reviews to search some of the more advanced digital intervention science in pediatrics (Multimedia Appendix 2). Our search strategy was guided and conducted by a medical librarian with extensive experience with systematic reviews; the list of search terms for specific chronic illnesses was modeled after published Cochrane reviews (eg, Law et al [36] on caregiver interventions for children with chronic illness). We excluded studies of interventions that target caregivers or health care providers only, interventions that target mental health problems/disorders not in the context of a chronic medical condition, prevention programs for healthy controls, disease and medication management programs, and programs in which the telehealth platform is only used to connect patients to providers via phone, text, or videoconference.

Selection of Studies

First, we screened titles and abstracts of studies retrieved for inclusion and exclusion. We then obtained full texts of articles designated as potentially meeting inclusion criteria to assess for eligibility. Screening of all titles, abstracts, and full-text articles was first independently double-coded by authors in pairs (NL, SW; NL, RP; NL, SFC); each dyad coded a subset of articles and NL coded all articles. Then, disagreements between the authors in each dyad were resolved through discussion while referencing the original source material to reach consensus. Finally, for articles meeting inclusion criteria, we independently double-coded relevant information from each study in pairs (NL, SW; NL, RP; NL, SFC), including study design, sample size, target illness, intervention characteristics (eg, intervention theory and components, eHealth or mHealth platform), and treatment outcomes data.

For intervention characteristics, we relied on authors' descriptions, either provided in the articles themselves or in prior publications of the intervention referenced in the included articles, and standard norms for psychosocial interventions. For example, if authors described an intervention as being based on cognitive behavioral theory, we coded the theory as cognitive behavioral; if the intervention followed a prespecified order mirroring the stepwise progression of traditional manualized evidence-based psychotherapies, it was coded as a modular treatment session per clinical norms [37]; and if patients could connect with research or psychosocial staff for support, we coded the intervention as human-assisted.

Unsurprisingly, measures collected in studies incorporated both psychosocial outcomes and physical health/disease-related outcomes. In the context of chronic medical conditions, physical and psychological consequences are intertwined and physical health/disease-related outcomes tend to improve alongside emotional and psychological functioning [38]. Outcome measures were categorized as either psychosocial (depression, social problem solving, fear and worry about symptoms, anxiety sensitivity, perceived stress, rewarding pain behavior, quality of life, social acceptance, family conflict, pain catastrophizing, psychological well-being, emotional functioning, parental protectiveness, anxiety, school attendance, self-efficacy, posttraumatic stress symptoms, somatic symptoms, coping strategies) or physical health/disease-related (fatigue, physical functioning, energy, disease symptoms, pain intensity and frequency, pain interference, pain reactivity, sleep, disease knowledge, activity limitations, functional disability). Categorizations were based on the psychosocial background literature [39-41] and agreed upon internally by our interdisciplinary research team which includes intervention science researchers, health services researchers, physicians, and psychologists; we acknowledge that some outcomes such as aspects of pain management, sleep, and functional impairments may fit either categorization. For study design, we used author designations. For example, a study was categorized as a pilot randomized controlled trial (RCT) if described as such in the article. We referred to the articles to resolve any discrepancies during consensus conversations and did not make inferences beyond authors' definitions and descriptions.

After review of the articles, the team determined that heterogeneity in outcome variables and measurement time points precluded meta-analysis. Thus, we described the data systematically.

Quality Assessment

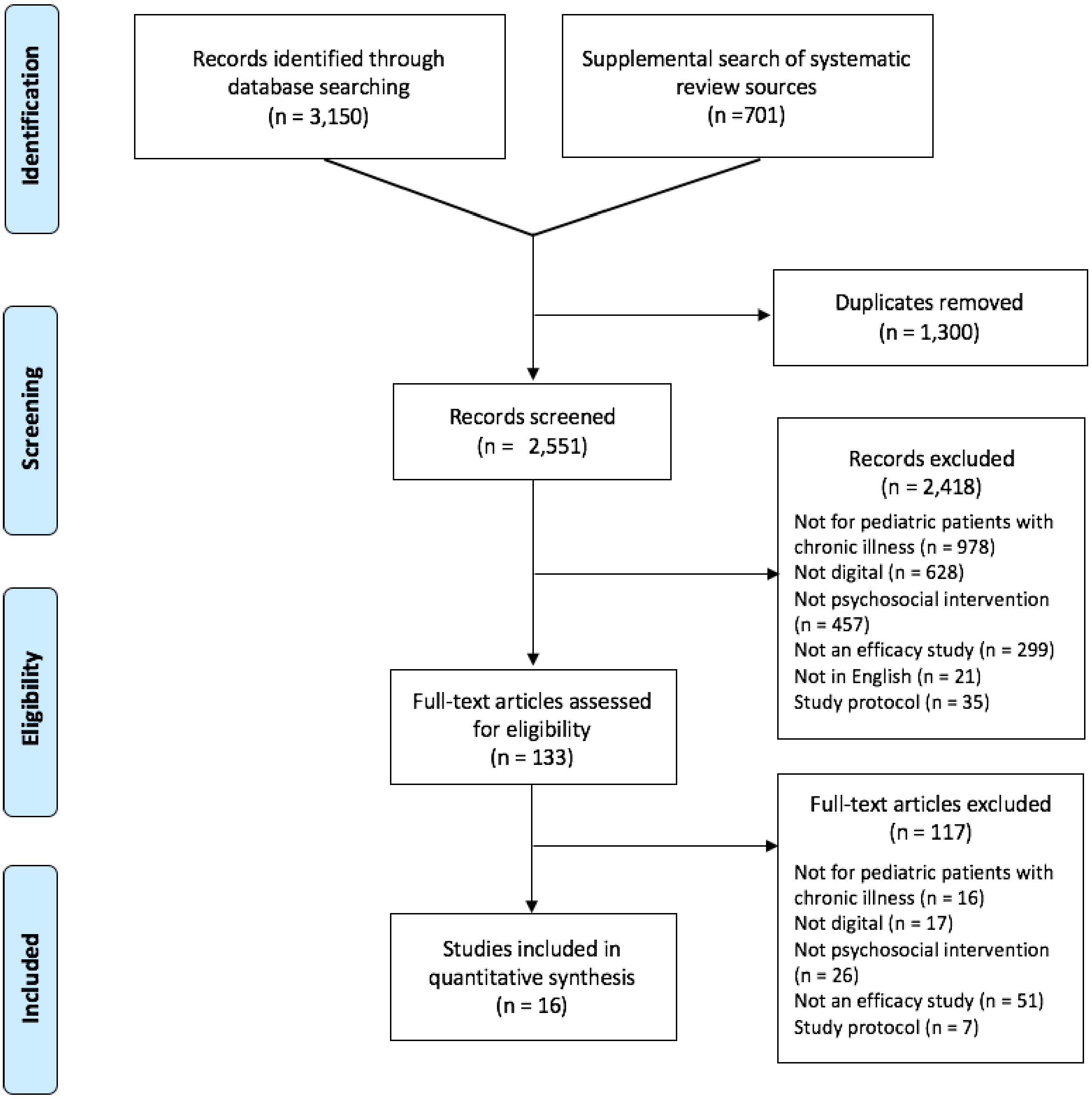
We independently assessed study quality in pairs (NL, SW; NL, RP; NL, SFC) using the Cochrane Collaboration's tool for assessing risk of bias [42] to evaluate random sequence generation (selection bias), allocation concealment (selection bias), blinding of participants and personnel (performance bias), blinding of outcome assessment (detection bias), incomplete outcome data (attrition bias), selective reporting (reporting bias), and other biases. We coded each category as low, high, or unclear risk of bias according to established standards in the Cochrane handbook for systematic reviews of interventions [43]. We resolved discrepancies in coding during regularly scheduled consensus meetings by referring to the journal articles themselves.

Results

Literature Search

The results of the search and selection of studies are described in the preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram (Figure 1). We screened 2551 articles; 2418 were initially excluded because they did not meet selection criteria. Evaluation of the remaining 133 relevant full-text articles resulted in the exclusion of 117 articles, leaving us with 16 articles that met criteria for inclusion. We provide a synthesis of the findings from the included studies structured around the type of intervention, target population characteristics, intervention content, and type of outcomes.

Figure 1. Preferred reporting items for systematic reviews and meta-analyses diagram.



Intervention Characteristics

We found 12 [44-60] unique digital interventions that were developed and tested in the United States [51,55,58], Australia [44], Canada [49,60], Germany [48,54], the Netherlands [47], and Sweden [45,61] (Table 1). Ten were eHealth interventions [44-48,51-59,61] and 2 mHealth interventions [49,60]. We found that over half (7/12, 58%) [45-48,53-58,61] were based on cognitive behavioral therapy principles [62,63]. Other treatment frameworks represented included disease self-management, problem solving, psychoeducation, and social-emotional learning. The interventions varied in length, duration, and number of sessions. All but two interventions incorporated modular treatment sessions that follow a prespecified order (Table 1).

Table 1. Interventions targeted for youth chronic illness populations.

Intervention name	Targeted illness	Age range[a]	Country of origin	Platform	Standalone intervention or supplement	Iterative design process	Modular or unstructured sessions	Intervention theory
Breathe Easier Online [44]	Chronic respiratory condition	10-17	Australia	eHealth	Standalone		Modular	Evidence-based social support and problem-solving program following PACE[b] principle
Fatigue in Teenagers on the InterNET [45]	Chronic fatigue syndrome	12-18	Netherlands	eHealth	Standalone		Modular	Evidence-based CBT[c]
iCanCope [60]	Chronic pain	15-18	Canada	mHealth	Standalone	x	Unstructured	Evidence-based psychological pain management, symptom monitoring
iCBT[d] for adolescents with FGID[e] [46,61]	Pain-prominent FGID	13-17	Sweden	eHealth	Standalone	x	Modular	Evidence-based iCBT
Move It Now [47]	Chronic pain	12-17	Netherlands	eHealth	Standalone		Modular	Evidence-based CBT
Onco-STEP [48]	Survivors of pediatric cancer	≥15	Germany	eHealth	Standalone		Modular	Evidence-based CBT
PainSquad+ [49,50]	Cancer pain management	12-18	Canada	mHealth	Standalone	x	Unstructured	Evidence-based pharmacological and psychological pain management strategies
TeenCope [51]	Type 1 diabetes	11-14	US	eHealth	Standalone	x	Modular	Evidence-based psychoeducational intervention based on coping skills training
Teens Taking Charge: Managing Arthritis Online [52]	Juvenile idiopathic arthritis	12-18	Canada	eHealth	Standalone	x	Modular	Evidence-based self-management strategies
Trautmann self-help programs: internet-based CBT, internet-based applied relaxation [53,54]	Recurrent headache	10-18[a]	Germany	eHealth	Standalone	x	Modular	Evidence-based CBT, relaxation
Web-based management of adolescent pain [55-57]	Chronic pain, recurrent headache, sickle cell disease	11-18[a]	US	eHealth	Standalone	x	Modular	Evidence-based CBT
Web-based treatment for adolescents with IBD[f] [58]	Inflammatory bowel disease	12-17	US	eHealth	Supplement to face-to-face	x	Modular	Evidence-based CBT

[a] Age range represents lowest and highest age range across all studies for the same intervention.

[b] PACE: problem identification, alternative solution generation, consequences of each alternative solution, execute solution and evaluate.

[c] CBT: cognitive behavioral therapy.

[d] iCBT: internet-based cognitive behavioral therapy.

[e] FGID: functional gastrointestinal disorder.

[f] IBD: inflammatory bowel disease.

All except two were human-assisted (10/12, 83%); human-assisted interventions allowed patients to connect with research or psychosocial staff (ie, psychologist, psychology trainee, nurse, peer counselor) for support via emails, texts, phone calls, private online messaging centers, or message boards (Multimedia Appendix 3). Half of the interventions (6/12, 50%) had some element of caregiver involvement [45-47,52,55-58,61]. Skills practice was notably the only component shared across all interventions. Other components incorporated that lend themselves well to digital intervention platforms include ecological momentary assessment, which allows symptom tracking in real time (4/12, 33%) [64]; tailoring of content to individual users (6/12, 50%); didactic videos (4/12, 33%); online discussion forums (6/12, 50%); and gamification to increase engagement (3/12, 25%).

Participants and Study Characteristics

Participant ages ranged from 10 to 18 years. The targeted chronic illnesses included diabetes, chronic pain, juvenile arthritis, cancer, chronic fatigue syndrome, recurrent headache, chronic respiratory condition, sickle cell disease, and gastrointestinal disorders (Table 1).

Of the 16 included efficacy studies (Tables 2 and 3), there were 3 single-site prospective cohort studies [44,53,57], 1 multisite prospective cohort study [52], 5 pilot RCTs (3 single-site [46,48,58], 2 multisite [49,60]), and 7 phase 2-3 RCTs (4 single-site [45,46,54,56,61], 3 multisite [47,55,59]). The 4 non-RCT prospective cohort studies were pilot studies with small sample sizes ranging from 2061 to 4049 participants with no comparison groups. For the pilot RCTs, sample sizes ranged from 1853 to 8357; one was described as powered for between-groups analyses [57]. The majority had an active treatment comparison condition, with only one using a wait-list control [56]. For the RCTs, sample sizes ranged from 4856 to 32,059; five were described as powered for between-groups analyses [45,55,56,59,61]. A little over half (4/7, 57%) [45,53-55,57,59,61] were compared with an active treatment condition, and the rest were compared with a wait-list control group.

Measures of psychosocial outcomes were collected across all studies, and physical health outcomes were collected in 88% (14/16) of studies [45-47,49,52-61] (Tables 2 and 3). However, outcomes assessed were heterogeneous, which prevents holistic synthesis across studies. At posttreatment, 56% (9/16) of the reviewed studies reported significant improvements in psychosocial outcomes (eg, anxiety, depression) [46,48,49,55,58,61]; effect sizes, where reported, ranged from small to large for RCTs and non-RCTs alike [46-49,55,58,61]. At posttreatment, half (8/16, 50%) [45-47,49,52,53,56] of the reviewed studies reported significant improvements in health-related outcomes (eg, physical functioning, disease knowledge); effect sizes, where reported, ranged from small to large for RCTs and non-RCTs alike [46,47,49,52,55,56,61]. In combination, a majority (11/16, 69%) of included studies reported some evidence of efficacy on psychosocial outcomes and/or health-related outcomes at posttreatment [45-49,52,53,55,56,58,59]. Findings across RCTs and non-RCTs were similar, with the exception that all non-RCTs reported some improvements in psychosocial outcomes.

Table 2. Original research publications with quantitative outcomes: randomized controlled trials only.

Intervention name	Type of study	Control group	Sample size	Powered for analyses?	Posttreatment outcomes[a,b]	Longitudinal outcomes[a,b]
Breathe Easier Online [44]	Pilot RCT[c]	Wait-list control	42		Psychosocial outcomes: no significant results for depression or social problem solving	N/A[d]
Fatigue in Teenagers on the InterNET [45]	RCT	Usual care	135	x	Psychosocial outcomes: intervention improved school attendance ($P≤.01$, 95% CI 2.7 to 8.9) Physical health outcomes: intervention improved fatigue ($P≤.01$, 95% CI 2.1 to 4.9) and physical functioning ($P≤.01$, 95% CI 2.3 to 6.3)	Psychosocial outcomes: intervention improved school attendance at 12 months Physical health outcomes: intervention improved fatigue and physical functioning at 12 months
iCanCope [60]	Pilot multisite RCT	iCanCope version A (symptom tracking only)	59		Psychosocial outcomes: no significant results for mood Physical health outcomes: no significant results for pain intensity and interference, physical activity, sleep quality, or energy	N/A
ICBT[e] for adolescents with FGID[f] [61]	RCT	Wait-list control	101	x	Psychosocial outcomes: intervention improved fear and worry about symptoms (95% CI 0.39 to 1.09, d[g]=0.74), and anxiety sensitivity (95% CI –0.07 to 0.47, d=0.20) No significant results for perceived stress or depressive symptoms Physical health outcomes: intervention improved gastrointestinal symptoms (95% CI 0.16 to 0.84, d=0.50) and pain intensity and frequency (95% CI 0.11 to 0.61, d=0.36)	Psychosocial outcomes: intervention improved fear and worry about symptoms (95% CI 0.59 to 1.59, d=1.05) and anxiety sensitivity (95% CI 0.10 to 1.04, d=0.57) at 6 months No significant results for perceived stress (95% CI –0.10 to 0.73, d=0.31) or depressive symptoms (95% CI –0.14 to 0.46, d=0.16) at 6 months Physical health outcomes: intervention improved gastrointestinal symptoms (95% CI 0.24 to 1.02, d=0.63) and pain intensity and frequency (95% CI 0.41 to 1.12, d=0.76) at 6 months
Move It Now [47]	Multisite RCT	Wait-list control	69		Psychosocial outcomes: intervention improved rewarding pain behavior by parents ($P≤.01$) and quality of life ($P≤.01$ to .04, d=–0.87 to 0.34) Physical health outcomes: intervention improved pain intensity (P=.03, d=–0.42), pain interference (P=.03, d=–0.46) and sleep problems ($P≤.01$, d=–0.60)	Psychosocial outcomes: intervention improved quality of life (besides mental health subdomain) at 3 months No significant results for rewarding pain behavior by parents at 3 months Physical health outcomes: no significant results for pain intensity, pain interference, or sleep problems at 3 months

Intervention name	Type of study	Control group	Sample size	Powered for analyses?	Posttreatment outcomes[a,b]	Longitudinal outcomes[a,b]
TeenCope [59]	Multisite RCT	eHealth managing diabetes psychoeducation for self-management	320	x	Psychosocial outcomes: no significant results for quality of life, social acceptance, self-efficacy, perceived stress, or diabetes family conflict Physical health outcomes: no significant results for HbA$_{1c}$[h]	Psychosocial outcomes: no significant results for quality of life, social acceptance, self-efficacy, perceived stress, or diabetes family conflict at 18 months Physical health outcomes: no significant results for HbA$_{1c}$ at 18 months
Teens Taking Charge: Managing Arthritis Online [52]	Pilot multisite RCT	Attentional control	46		Psychosocial outcomes: no significant results for quality of life, self-efficacy, or stress Physical health outcomes: intervention improved disease knowledge ($P≤.01$, d=1.32) and pain intensity (P=.03, d=0.78)	N/A
Trautmann self-help programs: internet-based CBT, internet-based applied relaxation [54]	3-arm RCT	Internet psychoeducation intervention	65		Psychosocial outcomes: no significant results for pain catastrophizing or psychological well-being Physical health outcomes: no significant results for headache frequency and duration	Psychosocial outcomes: no significant results for pain catastrophizing or psychological well-being at 6 months Physical health outcomes: no significant results for headache frequency and duration at 6 months
Trautmann's internet-based CBT [53]	Pilot RCT	Internet psychoeducation intervention	18		Psychosocial outcomes: intervention improved pain catastrophizing ($P≤.05$) Physical health outcomes: intervention improved headache frequency ($P≤.05$) No significant results for headache intensity or headache duration	Psychosocial outcomes: intervention improved pain catastrophizing ($P≤.05$) at 6 months Physical health outcomes: intervention improved headache frequency ($P≤.05$) at 6 months No significant results for headache intensity or headache duration at 6 months
Web-based management of adolescent pain						
	Multisite RCT [55]	Internet education control	273	x	Psychosocial outcomes: intervention improved emotional functioning (P=.04, d=–0.09) Physical health outcomes: no significant results for activity limitations, pain intensity, or sleep quality	Psychosocial outcomes: no significant results for emotional functioning at 6 months Physical health outcomes: intervention improved activity limitations (P=.03; d=–0.25) and sleep quality (P=.04, d=0.16) at 6 months No significant results for pain intensity at 6 months
	RCT [56]	Wait-list control	48	x	Psychosocial outcomes: no significant results for depression or parental protectiveness Physical health outcomes: intervention improved activity limitations ($P≤.01$, η^{2}[i]=.17) and pain intensity (P=.03, η^{2}=.11)	Psychosocial outcomes: no significant results for depression and parental protectiveness at 3 months Physical health outcomes: intervention improved activity limitations and pain intensity at 3 months

Intervention name	Type of study	Control group	Sample size	Powered for analyses?	Posttreatment outcomes[a.b]	Longitudinal outcomes[a.b]
	Pilot RCT [57]	Specialized headache treatment	83	x	Psychosocial outcomes: no significant results for anxiety or depression Physical health outcomes: no significant results for headache frequency, pain intensity, activity limitations, sleep duration, or sleep efficiency	Psychosocial outcomes: no significant results for anxiety or depression at 3 months Physical health outcomes: no significant results for headache frequency, pain intensity, activity limitations, sleep duration, or sleep efficiency at 3 months

[a] Only analyses of between-group differences comparing the intervention and control arms are reported.

[b] Information regarding confidence intervals, effect size, and *P* values is included when reported in the original research publication.

[c] RCT: randomized controlled trial.

[d] N/A: not applicable.

[e] iCBT: internet-based cognitive behavioral therapy.

[f] FGID: functional gastrointestinal disorder.

[g] *d*: Cohen *d*.

[h] HbA_{1c}: hemoglobin A_{1c}.

[i] η^2: eta squared.

Table 3. Original research publications with quantitative outcomes: nonrandomized controlled trials.

Intervention name	Type of study	Sample size	Posttreatment outcomes[a]	Longitudinal outcomes[a]
ICBT[b] for adolescents with FGID[c] [46]	Pilot study	29	Psychosocial outcomes: intervention improved stress (P<.05, 95% CI 0.02 to 0.69, d[d]=0.35) at posttreatment No significant results for anxiety or depression at posttreatment Physical health outcomes: intervention improved gastrointestinal symptoms (P<.05, 95% CI 2.37 to 10.58, d=0.50), pain interference (P<.05, 95% CI 0.11 to 0.61, d=0.36), and pain reactivity (P<.05, 95% CI 0.39 to 1.09, d=0.74) at posttreatment No significant results for functional disability at posttreatment	Psychosocial outcomes: intervention improved anxiety (P<.05, 95% CI 0.08 to 0.81, d=0.44) at 6 months No significant results for depression or stress at 6 months Physical health outcomes: intervention improved gastrointestinal symptoms (95% CI 3.43 to 12.21, d=0.63), pain interference (P<.05, 95% CI 0.41 to 1.12, d=0.76), pain reactivity (P<.05, 95% CI 0.59 to 1.59, d=1.05), and functional disability (P<.05, 95% CI 0.10 to 1.04, d=0.56) at 6 months
PainSquad+ [49]	Multisite pilot study	40	Psychosocial outcomes: intervention improved emotional functioning (P≤.01, d=0.66), social functioning (P≤.01, d=0.46), and overall HRQOL[e] (P=.02, d=0.43) at posttreatment No significant results for self-efficacy, or school functioning at posttreatment Physical health outcomes: intervention improved pain intensity (P≤.01, d=0.67) and pain interference (P=.03, d=0.38) at posttreatment No significant results for physical functioning at posttreatment	N/A
Onco-STEP [48]	Pilot study	20	Psychosocial outcomes: intervention improved posttraumatic stress symptoms (P≤.01, d=0.63), anxiety (P≤.01, d=0.74), fear of progression/relapse (P<.05, d=0.48), and depression (P≤.01, d=1.0) at posttreatment	Psychosocial outcomes: intervention improved posttraumatic stress symptoms (P<.01), fear of progression/relapse (P<.01), and anxiety (P<.01) at 3 months No significant results for depression at 3 months
Web-based treatment for adolescents with IBD[f] [58]	Pilot study	24	Psychosocial outcomes: intervention improved somatic symptoms (P≤.01, η^2[g]=.41), approach coping strategies (P≤.01, η^2=.43), distraction techniques (P≤.01, η^2=.35), protective parenting behaviors (P=.03, η^2=.27) at posttreatment Physical health outcomes: no significant results for abdominal pain at posttreatment	Psychosocial outcomes: intervention improved protective parenting behaviors (P=.01, η^2=.44) at 6 months No significant results for somatic symptoms, approach coping strategies, or distraction techniques at 6 months Physical health outcomes: no significant results for abdominal pain at 6 months

[a] ICBT: internet-based cognitive behavioral therapy.

[b] Information regarding confidence intervals, effect size, and P values are included when reported in the original research publication.

[c] FGID: functional gastrointestinal disorder.

[d] d: Cohen d.

[e] HRQOL: health-related quality of life.

[f] IBD: inflammatory bowel disease.

[g] η^2: eta squared.

A subset of 75% (12/16) of studies [45-48,53-59,61] evaluated longer term assessment time points ranging from 3 to 18 months (Tables 2 and 3). Nine studies (9/16, 56%) [45-48,53,55,56,58,61] showed promise of longer term gains from the intervention.

Risk of Bias

Risk of bias was evaluated for all included studies (Figure 2). Of the 16 studies, 12 reported random sequence generation and allocation concealment (ie, the pilot RCTs and RCTs). For the blinding of participants and personnel domain, 10 were high risk and 6 low risk; high-risk studies consisted of study designs with no control group or a wait-list control group. For the blinding of outcome assessment domain, 9 were high risk and 7 low risk. For attrition bias, 8 were low risk, 5 high risk, and 3 unclear; note that attrition rates for internet-based interventions (with an anchor point of around 50%) tend to be higher than traditional face-to-face psychosocial interventions [65]. For selective reporting bias, studies were split in half between low risk and unclear; studies were rated as unclear due to a lack of clinical trial registration or published protocol. For other biases, 12 were considered low risk and 4 high risk.

Figure 2. Risk of bias.

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Blinding of outcome assessment (detection bias)	Incomplete outcome data (attrition bias)	Selective reporting (reporting bias)	Other bias
Bonnert et al. 2014	−	−	−	−	?	?	+
Bonnert et al. 2017	+	+	−	−	+	+	+
Grey et al. 2013	+	+	+	+	−	+	+
Jibb et al. 2017	−	−	−	−	?	?	+
Lalloo et al. 2019	+	+	+	+	+	+	+
Law et al. 2015	+	+	+	+	?	?	+
McCormick et al. 2010	−	−	−	−	−	?	−
Newcombe et al. 2012	+	+	−	−	+	+	+
Nijhof et al. 2012	+	+	−	−	+	+	+
Palermo et al. 2009	+	+	−	−	+	?	+
Palermo et al. 2016	+	+	+	+	+	+	+
Seitz et al. 2014	−	−	−	+	−	?	+
Stinson et al. 2010	+	+	−	−	+	+	−
Trautmann et al. 2008	+	+	+	+	+	?	−
Trautmann et al. 2010	+	+	+	+	−	?	−
Voermann et al. 2015	+	+	−	−	−	+	+

Discussion

Overview

A majority of youth with chronic illnesses struggle with issues that psychosocial interventions effectively manage such as anxiety, stress, depression, maladjustment, pain, and poor coping skills [4,7]. Within the past decade, digital health interventions have been increasingly popular with widespread access to the internet and smartphones. To our knowledge, this is the first systematic review summarizing the research evidence in support of the efficacy of eHealth and mHealth psychosocial interventions for youth chronic illnesses. Each of the interventions identified was designed for a specific chronic illness population. The state of the science is still in its nascent stages, with only 16 published efficacy studies of 12 unique interventions identified. We provided information on the structure and content of included interventions and relationships between each of the interventions and various psychosocial and health outcomes. Given the substantial number of studies in which full articles were reviewed for eligibility (n=133, Figure 1), this points to growing interest in digital interventions for youth with chronic illnesses. Few digital interventions have advanced to the stages of efficacy testing (n=16), and even fewer in an RCT with an active comparison condition (n=8). This systematic review suggests that disseminating traditional evidence-based psychotherapies via novel digital health technologies may be efficacious.

Consistent with evidence-based digital health practices and recent systematic reviews of digital interventions with youth chronic illness and mental health populations [17,24,25,28,33], our systematic review of eHealth and mHealth psychosocial interventions for youth chronic illness populations found (a) early evidence of improvements in psychosocial and physical health outcomes immediately posttreatment; (b) early evidence of the maintenance of treatment gains at longer term follow-up extending to 3+ months; (c) a prevalence of computerized cognitive behavioral therapy interventions; (d) varying levels of psychosocial staff support via text, email, phone, online discussion forums, or private online messaging centers; and (e) key methodological limitations for a majority of included studies such as lack of blinded outcomes assessment, limited number of RCTs, and few studies with active treatment comparison groups.

This review also suggests several gaps in the existing literature. Future research should focus on optimizing digital intervention design and implementation, namely how to efficiently streamline resource-intensive personnel assistance and encourage self-direction in order to sustain intervention efficacy and engagement while minimizing costs [66]. Notably, only two of the included interventions did not involve some form of contact with providers or research staff. In addition to clinician involvement, given that half of the interventions reviewed included caregiver support, new digital intervention research should continue to explore the additive value of caregiver involvement where appropriate with unique content designed for parent caregivers [55,56]. Next, as each of the interventions included in our review was designed for a specific chronic illness, further research is needed to ascertain whether a disease nonspecific transdiagnostic approach [67,68] to designing digital psychosocial interventions applicable across heterogeneous disease groups is warranted. In particular, online mindfulness-based interventions have been shown to be successful in chronic illness and other populations [69-71]. Interventions also had multiple components, which may benefit from dismantling studies to identify which active therapeutic ingredients lead to positive outcomes [72]. Similarly, emphasis should be placed on identifying and targeting the aspects of digital engagement that lead to the intended behavior change rather than just encouraging more frequent use [73]. The use of analytics in eHealth and mHealth can provide invaluable insights into active therapeutic ingredients, aspects of effective digital engagement, treatment moderators (for whom interventions work), and treatment mediators (how treatments work) [74,75]. Finally, future studies might assess the value of more novel technologically enabled features such as just-in-time adaptive intervention designs (JITAIs). Indeed, JITAIs use causal modeling to identify the appropriate type and dose of intervention at the optimal point in time by measuring and responding to an individual’s changing health states [76,77]. These innovative programs have the potential to meet evolving real-time needs of youth at risk.

Given the interest in and rapidly changing landscape of digital health, it is likely that new publications have been released during the typical time frame it had taken us to rigorously complete our systematic review. We intend to publish a 5-year systematic review update populated with new efficacy studies and trials. The median timing of Cochrane systematic review updates is greater than 5 years [78]. Although previous research suggests only 4% of systematic review updates report a change in conclusions [79], our overarching findings may be subject to change given the limited number of included studies and the quickly evolving digital health landscape.

Limitations

Limitations to consider are as follows. First, most of the interventions were designed and tested as web-based eHealth interventions, with only two mHealth intervention designed for use on smartphone devices. We anticipate that more mHealth interventions will be tested for efficacy and come down the pipeline in the years to come as smartphones become more and more ubiquitous. Previous research suggests that mHealth apps are widely accepted by the general public for coping skills and stress management, and beliefs and attitudes toward mHealth are positive [80]. Second, the majority of studies were not powered to detect meaningful changes in health outcomes of interest nor did they designate primary versus secondary outcomes in their research designs. Third, only half of the studies used an active treatment comparison condition or blinded participants to assigned treatment condition, and findings of favorable treatment response may be susceptible to the placebo effect [81]. Fourth, there exists the possibility of publication bias because nonsignificant findings are often difficult to publish. Fifth, although our search was executed by a medical librarian in five well-established library databases, other databases to which our university does not have access (eg, Scopus) may have uncovered additional relevant publications. Finally, given the heterogeneity of disease groups, measurement time points, and study outcomes measures, it was not possible to conduct a meta-analysis and provide synthesized results of the efficacy studies included in our systematic review.

Conclusions

The strengths of this paper include the systematic approach to synthesizing the great breadth of literature across pediatric illness populations and the eHealth and mHealth focus increasingly popular among youths. This publication is especially timely given heightened psychological distress and exacerbating mental health symptoms for youth in the context of the COVID-19 pandemic, in-home confinement, school closures, social distancing, and a shift toward online and telehealth services [82-85]. We found intervention features unique to digital platforms such as gamification, ecological momentary assessment, and machine learning algorithms. Such features capitalize on technological advances to intervene during distressing situations in real time and tailor content to individual preferences and needs. Leveraging such technological advances allows movement toward a data-driven and personalized approach to precision mental health [86]. The state of the science is still in its early stages, and further clinical trials research is needed to confirm whether evidence-based psychosocial interventions traditionally delivered in-person may be successfully translated to digital formats for a range of youth chronic illness populations.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Primary search strategy.
[DOCX File , 22 KB - pediatrics_v3i2e22329_app1.docx]

Multimedia Appendix 2
Supplemental search strategy.
[DOCX File , 20 KB - pediatrics_v3i2e22329_app2.docx]

Multimedia Appendix 3
Intervention and personnel-supported components.
[DOCX File , 21 KB - pediatrics_v3i2e22329_app3.docx]

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Abbreviations

JITAI: just-in-time adaptive intervention design
mHealth: mobile health apps
PRISMA: preferred reporting items for systematic reviews and meta-analyses
RCT: randomized controlled trial

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Review

Usability of eHealth and Mobile Health Interventions by Young People Living With Juvenile Idiopathic Arthritis: Systematic Review

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Abstract

Background: Considering the changing landscape of internet use and rising ownership of digital technology by young people, new methods could be considered to improve the current model of juvenile idiopathic arthritis (JIA) management.

Objective: This systematic review aims to evaluate the usability of eHealth and mobile health (mHealth) interventions currently available for young people living with JIA.

Methods: The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines were used to oversee this review. We systematically searched 15 databases for 252 potential studies; 2 authors independently screened all quantitative studies reporting the use of eHealth and mHealth interventions for young people (aged 1-18 years) diagnosed with JIA. Studies were excluded if they did not report outcome measures or were reviews, commentaries, or qualitative studies. Study methodological quality was scored using the Down and Black (modified) checklist. A narrative descriptive methodology was used to quantify the data because of heterogeneity across the studies.

Results: A total of 11 studies were included in this review, reporting 7 eHealth and mHealth interventions for young people (aged 4-18 years) living with JIA, targeting health issues such as pain, health-related quality of life, physical activity, and chronic disease self-management. The usability of the interventions was facilitated through training and ongoing support. The engagement was promoted by a combination of persuasive influences, and barriers preventing adherence were removed through personal reminders and flexible program schedules to cater to JIA and non-JIA illnesses or other commonly seen activities in childhood. The feedback obtained was that most young people and their parents liked the interventions.

Conclusions: The results of this review need to be considered cautiously because of the lack of rigorous testing and heterogeneity, which limits the detailed descriptions of data synthesis. Further research is needed to consider gender differences, associated costs, and the effectiveness of the interventions on health outcomes to better support young people living with JIA.

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KEYWORDS

juvenile idiopathic arthritis; child; adolescence; eHealth; mHealth; systematic review; mobile phone; pain; physical activity; self-management; quality of life

Introduction

Background

Juvenile idiopathic arthritis (JIA) is the most common type of arthritis in young people [1,2] with an incidence rate of 1.6 to 42.5 per 100,000, varying across different geographical locations and ethnic groups [3-6]. Symptoms include an unpredictable trajectory of joint inflammation [7], stiffness [8], pain [9], and fatigue [10] that can persist into adulthood. The active disease can impair functional ability [11,12], school attendance [13], and sleep [14], increasing the risk of poor psychosocial health [13], social isolation, reduced exam performance [15] and career prospects [16], affecting the quality of life [10,17,18]. At present, there is no definitive cure; instead, the current best practice supports timely interventions customized to manage inflammation, thus controlling pain, improving quality of life, and preventing long-term disability [18,19].

Improving the JIA Model of Care

Responding to the needs of young people living with JIA is a challenge because of the problems in the current model of care [19,20]. A worldwide shortage of pediatric rheumatologists (PR) has limited most pediatric rheumatology services to tertiary children's hospitals, typically based in major capital cities. Services are also based on a retrospective method of health care delivery, where appointments are made 3 to 6 months in advance, which is slow to react to a patient's changing conditions [20-25].

Feedback from parent and carer surveys also suggests that pediatric rheumatology services need to improve the quality of their service and the patients' experience. Responses suggest they need to optimize their efficiency, improve information exchange [26,27], promote ongoing interdisciplinary support networks [26-28], and improve access to a JIA experienced clinician when needing urgent advice [27] or experiencing an unpredictable flare of disease, complications, adverse reactions [26], or illness [28].

Improving Self-Management Behavior

Good self-management behavior has a positive effect on health outcomes [29]. Young people with JIA and their families need to be encouraged to take an active role in their disease management [30] and be provided with meaningful opportunities to develop the skills they need to support self-management [29]. This is important because young people do not automatically develop these skills [31], and they are not overly concerned about their long-term health outcomes. Instead, they are more concerned with the present [32], making disease management secondary to their school and social activities [33].

Digital Solutions

An innovative way to improve the current care model and foster self-management skills could be through eHealth or mobile health (mHealth) interventions [34-36], in particular, when considering the changing landscape of internet usage [37] and rising ownership of digital technology by young people [38]. A growing generation of digital natives is inadvertently turning to digital solutions to support their daily lives [34,39]. From a young person's viewpoint, digital technology can promote a better understanding of their disease, support self-management, and remove the need for constant supervision by parents and clinicians [36]. From a clinician's perspective, digital technology can facilitate health promotion and allow real-time symptom monitoring [34,36], potentially enabling timely changes to treatments and the prevention of flare-ups, thereby improving health outcomes and decreasing health care costs.

Critical to the success of any digital intervention is the manner in which young people accept and interact with the technology [38,40,41]. This understanding is often uncovered in usability testing. In recent years, usability testing has shifted from traditional technology testing to understanding and optimizing the users' experience [41-43] because user feedback can be different from the planned use of the intervention [43]. Usability testing that pursues a user-led design [35,41], particularly for specific populations, uncovers problems related to acceptability, perceived level of usefulness, and adherence. Aiding the delivery, uptake, and retention of an accessible intervention that fits into a young person's lifestyle and meets the needs of a wide and diverse range of users [44-47].

Definition of eHealth and mHealth

eHealth is described by the World Health Organization (WHO) as an activity that delivers health-related information, resources, and services through electronic technology and internet connectivity [48]. mHealth is described as a mobile and wireless form of technology for medical and public health practices [41].

Aim and Rationale

This systematic review presents the first of 2 steps in evaluating the clinical use of eHealth and mHealth interventions for young people (aged 1-18 years) living with JIA. This review aims to evaluate quantitative studies examining the usability of eHealth and mHealth interventions to understand how young people interact with the technology. The following 3 areas were considered:

1. Identification of the digital health intervention.
2. Usability (delivery of the intervention) [47,48].
3. Costs associated with the intervention [48].

It is anticipated that such information will improve our understanding of the mechanisms that support the use of these interventions by young people living with JIA and inform future development. The second step of this review aims to evaluate the effectiveness of interventions. These results will be published subsequently in another review.

Methods

Overview

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) statement [49] guided this review (Multimedia Appendix 1). The protocol for this systematic review was registered on PROSPERO (International Prospective Register of Systematic Reviews; ID CRD42018108985) [50].

Eligibility Criteria

Participants

All young people (aged 1-18 years) diagnosed with JIA using the International League of Associations for Rheumatology criteria [51] were considered eligible.

Interventions

Any eHealth or mHealth interventions (see definition in the *Introduction*) delivered through an electronic device with internet connectivity [46] or wireless capacity were eligible [52].

Comparator/Control

No comparator was used.

Outcomes

We considered an outcome as any quantifiable measure specifically targeting the pediatric population or pediatric rheumatology.

Study Design

All quantitative studies reporting the use of eHealth and mHealth interventions for young people (aged 1-18 years) diagnosed with JIA were included. Studies were excluded if they did not report outcome measures or were reviews, commentaries, or qualitative studies.

Search Strategy

To develop search terms, MEDLINE and CINAHL were initially searched by SB to identify keywords in the titles, abstracts, and indexed terms. In October 2018, the search terms were adapted to suit the controlled vocabulary, Boolean operators, truncation, and wildcards in MEDLINE/PubMed, the Cochrane Library, Joanna Briggs Institute, AMED (Allied and Complementary Medicine Database), CINAHL complete, EMBASE, JAMA (Journal of the American Medical Association), Informit Health, ProQuest database, PsycINFO, IEEE (Institute of Electrical and Electronics Engineers and Institution of Engineering and Technology) Xplore, SAGE Publishing, ScienceDirect, Scopus, and Web of Science. Further studies were retrieved from Google Scholar and arthritis-related organizations (Arthritis Australia, Arthritis Foundation, and Childhood Arthritis and Rheumatology Research Alliance funded projects and conferences) and by hand searching reference lists. The search strategy was not restricted by language or year of publication. The database search was repeated in November 2019 (Multimedia Appendix 2).

Study Selection

Two authors (SB and AC) independently reviewed all studies retrieved by the search strategy via individual log-in systems on the web-based platform Covidence [53]. Titles and abstracts were reviewed against the inclusion and exclusion criteria and full-text versions. Authorship and results were not masked, and any disagreements were discussed and resolved by SB and AC. To gain access to all full-text studies, corresponding authors were contacted by email, or the full text was retrieved by the University of Newcastle library interlibrary request service *Get It*. There was no need for translation sources; only 1 study was retrieved in a language other than English (Dutch), and an English version of the same study was attained through ResearchGate.

Data Collection

A data extraction Excel (Microsoft) form was designed to collect all relevant information from the studies, including participant demographics, eHealth or mHealth characteristics, study design, study outcomes, and costs. Conclusions were drawn from the outcomes reported by study authors. Data extraction was completed by SB and checked by all reviewers.

Risk of Bias

Using the Down and Black (modified) checklist for randomized and nonrandomized studies [54,55], studies were rated independently by 2 reviewers (SB and AF). This checklist has a high correlation with similar tools for validity (r=0.90) and reliability (r=0.69-0.90) [54,55]. The checklist considers 5 main assessment areas: (1) reporting; (2) external validity; (3) internal validity, bias; (4) internal validity, cofounding and selection bias; and (5) power; it provides an overall score out of 28 [56]. Across the studies, a disagreement rate of only 7.6% arose (13 of 170 questions), which was resolved through discussion (SB and AF) and re-examination of the studies.

Summary Measures

To summarize the participants' characteristics, the mean scores reported by the study authors were averaged. The range of data was determined by the reported highest and lowest values. Individual JIA subtypes were combined and expressed as the total number (n) and the proportion of each subtype as a percentage (%). The total number of studies including the information required was stated (ie, "4 studies reported…") to account for missing data.

Synthesis of Results

Meta-analysis was considered unsuitable for this systematic review because of the heterogeneity across the studies and the different intervention development stages. Instead, a narrative synthesis methodology was used to allow the data to be organized, explored, and presented in a logical way [57] to uncover potential similarities and differences, associations, and patterns within the results [57,58]. The 4 stages of analysis suggested by Popay et al [58] were adapted and used to guide this review.

1. Develop a theoretical model to understand how the intervention works.
2. Conduct a preliminary synthesis to:

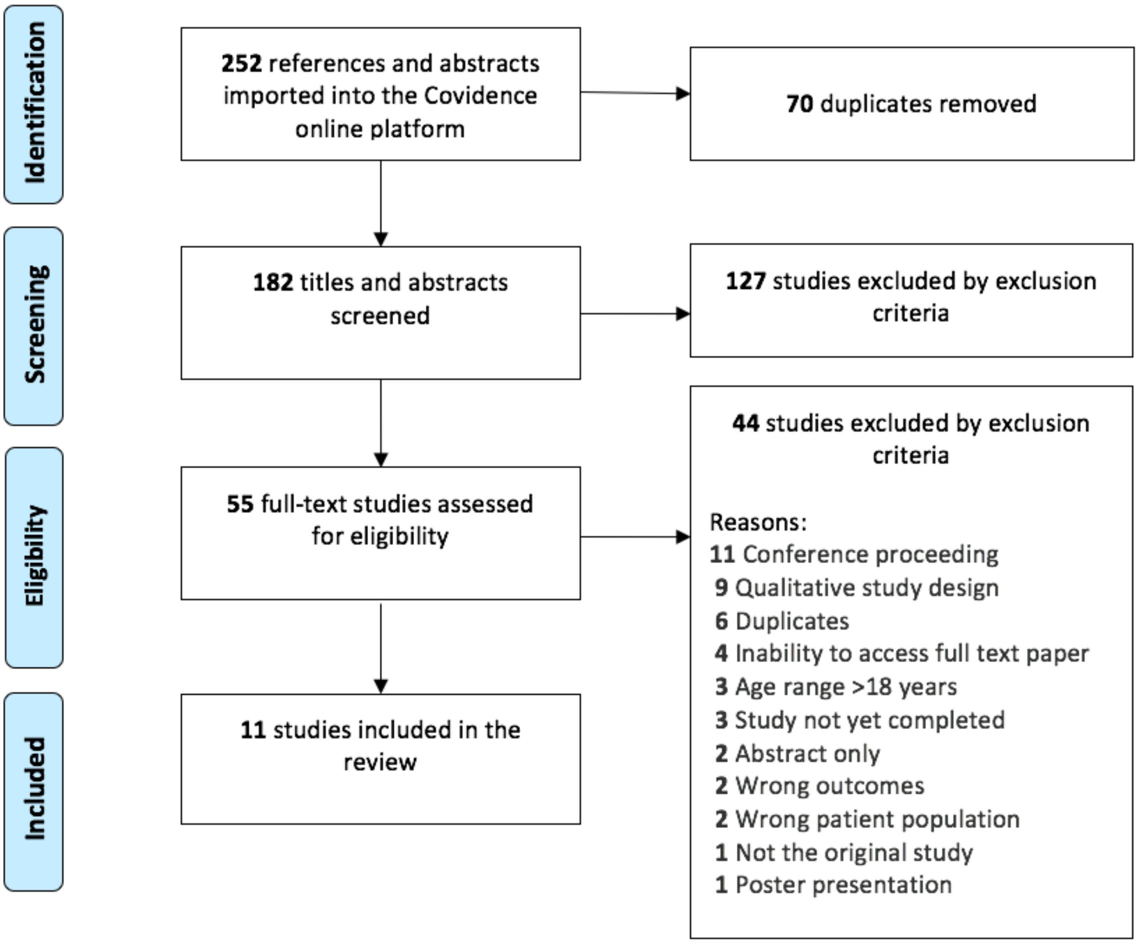
  - identify factors supporting implementation and barriers;
  - consider relationships among studies.
3. Perform a content analysis (translation of data) to:
  - report characteristics among studies;
  - identify moderator variables;
  - develop numerical/statistical rubrics.
4. Draw a conclusion by critically reflecting on methodology synthesis.

Results

Study Selection Process

A total of 252 studies were identified using the search strategy. After removing 70 duplicates, 127 studies that did not meet the inclusion criteria based on their title or abstract and 44 based on the full-text screening, a total of 11 studies met the inclusion criteria for this review (Figure 1).

Figure 1. Summary of the study selection process using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram.



Study Characteristics

Participants

This review included 634 participants [59-67]; 57.1% (362/634) of participants were recruited from either pediatric rheumatology departments or clinics affiliated to a hospital, and 42.9% (272/634) of participants from pediatric tertiary care centers. Study sample sizes ranged from 13 to 176 participants and varied in age (mean 12 years, SD 2.5; range 4-18.6 years), gender (female: 429/602, 71.3%; mean 42.9, SD 31.6), and JIA subtypes (Table 1) [59-67]. To avoid duplication, a total of 2 studies were excluded from this analysis [68,69], because the participant characteristics were reported in another study included in this review [61,67]; furthermore, 3 studies did not report participants characteristics when participants were lost in follow-up (32/634, 5.0%), reducing the age and gender analysis to 602 of 634 participants [60,61,63].

Table 1. Juvenile idiopathic arthritis subtypes, based on the International League of Associations for Rheumatology criteria.

Juvenile idiopathic arthritis subtypes	Value
Oligoarthritis[a], n (%)	195 (30.8)
Polyarthritis[b], n (%)	172 (27.1)
Polyarthritis (rheumatoid factor positive), n (%)	41 (6)
Enthesitis related, n (%)	54 (8)
Systemic, n (%)	46 (7)
Psoriatic, n (%)	33 (5)
Undifferentiated, n (%)	7 (1)
Unknown or not yet diagnosed or other, n (%)	39 (6)
Chronic arthritis with other/or other forms of rheumatic disease[c], n (%)	13 (2)
Not recorded, n (%)[d]	34 (5)
Disease activity (cm), mean (range)[e]	1.8 (0.2-3.7)
Disease duration, mean (range)[f]	5 years (<1 month-15.65 years)

[a] Includes the subcategories of oligoarthritis: persistent and extended [60,62-64,66].

[b] Includes 2 studies not reporting positive or negative rheumatoid factor. [63,67].

[c] Juvenile dermatomyositis, systemic lupus erythematosus [62,63].

[d] Reasons: drop-out, loss of follow-up (n=32) [60,61,64] and missing subtypes (n=2) [64]

[e] A total of 8 studies reported disease activity [59,60,62,63,65-68].

[f] A total of 7 studies reported disease duration [60,62,64-68].

Intervention

The 11 studies included in this review reported 7 interventions, describing varying stages of development (preprototype to maturity); 4 interventions were web-based programs [61-65,68], 1 intervention was a computer-mediated electronic peer mentoring program (e-mentoring) [60], and 2 interventions used mobile technology for real-time monitoring [66,67,69]. The clinical significance of interventions aimed at improving self-management behavior [59-61,64,65,68] or supporting clinical decisions [62,66,67,69]. These interventions included the following:

1. *Misfit Flash*, a commercially available wearable tracker to improve physical activity [59].
2. *Rheumates@Work*, a web-based educational and cognitive behavioral program to improve self-management and physical activity [61,64,68].
3. *iPeer2Peer Program*, an online peer mentoring program to facilitate positive role modeling and social support through video calls [60].
4. *eOuch*, a customized electronic pain diary to self-report real-time pain [66,67,69].
5. *ePROfile* a web-based assessment (Kwaliteit van leven in kaart, or, quality of life map [KLIK] website) to self-report health-related quality of life (HRQoL) issues [62].
6. *SUPER-KIDZ*, a web-based pain assessment to self-report real-time pain [63].
7. *Teens Taking Charge: Managing Arthritis Online*, a web-based program to provide disease-specific information and self-management strategies [65].

Custom-designed programs designed by the research team were used in 5 interventions [61-69], and 2 interventions were commercially available [59,60]. The equipment necessary to operate these interventions included computers, laptops, handheld PDAs, an Apple iPod touch, and a wearable accelerometer synchronized to a smartphone. This allowed the interventions to be used at the participants' home [59-62,64-69] or clinic [62,63] (Multimedia Appendix 3).

Outcomes

Study outcomes considered feasibility, usability, efficiency, and/or effectiveness. To align usability outcomes with research questions 2 and 3, usability outcomes were synthesized to form 4 themes: (1) user engagement (promotional activities and adherence), (2) barriers preventing usability (personal, technical, and device barriers), (3) user feedback (acceptability and satisfaction), and (4) cost assessment (basic financial costs). Themes were based on 5 of 16 areas of reporting by Agarwal et al [41] to improve the quality of evidence being extracted. The remaining areas of reporting are beyond the scope of this review (Table 2).

Table 2. Formation of themes, evaluation criteria, and main outcomes supporting the delivery of the eHealth and mobile health interventions for juvenile idiopathic arthritis.

Research question, theme, and evaluation criteria	Outcomes
Research question 2	
User engagement	
Promotional activities	Adoption inputs [59-61,64-69]
Adherence	Activity log, dropout [59] participation rate [68], program adherence [60,64], commitment, level of interaction [61], program compliance [65-67,69], and safety [59,60,64]
Barriers preventing usability	
Personal barriers, technical barriers, or device barriers	Device malfunction rate [59], barriers preventing engagement [59], technical problems [61,63,66], missed responses [63], or errors [67]
User feedback	
Acceptability	Questionaries [60,63,65] and evaluation questionnaire [66,67]
Satisfaction	Questionaries [60-63,65], semistructured phone interview [60], and evaluation of use [62]
Research question 3	
Cost assessment	
Basic financial cost (owing to no comparator)	Cost (adding together development of the program, staff costs, financial consequences ie, traveling expenses and babysitters) [61]

Study Design

The study design included 4 descriptive studies, 3 pilot randomized controlled trials (RCTs), 1 multicenter RCT, 1 pre- and postintervention design, 1 correlational research design, and 1 sequential cohort study—studies reported from 2 high-infrastructure countries, Canada [59,60,63,65-67,69] and the Netherlands [61,62,64,68] (Multimedia Appendix 4).

Methodological Quality of Studies

The methodological quality of study scores ranged from 15 to 21 out of 28 (mean score 18.6, SD 1.9), a fair to good score [54]. Convenience sampling and/or selection bias meant that study participants may not fully represent the JIA population. Participants were selected according to disease activity, pain, the unlikelihood of medication changes, level of physical activity, owning a computer/tablet/interactive mobile phone, availability of the internet, and literacy levels ([59-69]) Multimedia Appendix 5.

Results of Studies-Delivery of the Intervention

Theme 1: User Engagement

Promotional Activities

All studies reported promotional activities to support engagement with the intervention. The top 2 included training [59-63,65] and ongoing human communication [60,61,64-66] (Table 3).

Table 3. Promotional activities used to support engagement with the intervention for juvenile idiopathic arthritis.

Promotional activity	Misfit flash	Rheumates@Work	ePROfile	iPeer2Peer	eOuch	SUPER-KIDZ	Teens taking charge
Training	Y[a]	Y	Y	Y	Y	Y	Y
Instruction manual	Y	—[b]	—	—	Y	—	—
Goals set by users	Y	Y	—	—	—	—	Y
Ongoing technical support	—	Y	—	—	Y	—	Y
Personal reminders	—	—	—	—	Y	—	—
Ongoing human communication	—	Y	—	Y	Y	—	Y
Reactive feedback loop	—	Y	—	—		—	—
Linear design	—	Y	—	—	Y	—	Y
Interactive content	—	Y	—	—		—	Y
Flexibility in length of the program	—	Y	—	Y		—	Y

[a] Y: yes.

[b] The promotional activity listed was not used.

Training

All interventions provided participants and/or parents with training (range <5-20 min) [59-63]. Training sessions included how to use the software [69], functionality [59,69], demonstration and practice using pain vignettes [66,69], and instruction on completing learning modules and pain entries [61,66]; 3 interventions also provided training for those supporting the intervention: PRs, peer mentors, and a coach [60,62,65]. One study reported flexibility in training, delivering training at the participant's home or clinic [67] (Multimedia Appendix 2).

Ongoing Human Communication

Throughout the study period, 4 interventions provided ongoing human communication [60,61,64-66,68]. Human communication included telephone support [60,61,64-66], emails [60,64,65], face-to-face group sessions [64,68], daily monitoring of discussion boards [60,65], peer support [60, 65], and an online chat room [61]. A good-quality study, *Teens taking charge: managing arthritis online*, considered the use of a coach, providing weekly telephone calls as a necessary part of the intervention, reporting 1.6 calls (mean duration 17.3 min, range 7-30 min) each week for the intervention group (IG) [65]. After the study period, the control group (CG) was given access to the intervention, without the coach and telephone support. Website engagement dropped compared with the IG, from 436.9 to 6.42 hours. Similarly, interaction by parents of the CG reduced from 458 to 19 hits [65].

Safety Support

A total of 3 fair to good–quality studies monitored participants' safety [59,60,64]. The *iPeer2Peer Program* reported that all Skype calls were recorded and reviewed within 24 hours by a research team member. The peer mentor was also trained to flag concerns [60]. For *Rheumates@Work*, the PR maintained disease activity and medication usage records, reporting disease flare-ups for 3 participants (IG, n=1/17; CG, n=2/16), and no adverse events [64]. *Misfit Flash*, reported illness, injury, or pain for 9 participants due to being active (n=9/28) and arthritis-related pain for 1 participant (n=1/28). However, no significant difference was reported for pain, functionality, or disease activity during the study period [59].

Adherence Rates

All interventions had an expected level of engagement, ranging from minutes to 17 weeks [59,60,62-69]. A total of 8 fair to good–quality studies monitored adherence rates (range 70%-82.1%) [59-61,63-67,69]; 4 studies increased adherence by allowing more time to complete the intervention [60,61,64,65], and 1 study increased adherence to 100% (n=46) [65] ([59-61,64-67,69] Multimedia Appendix 6).

Week to Week and Time of Day Adherence

A significant difference was seen in adherence in pain reporting, using the eOuch pain diary, by 2 fair to good quality studies, week to week and according to the time of day (Multimedia Appendix 6) [66,67]. Adherence rates were increased 10% across the day by adjusting the preset pain reporting reminder alarms (morning, on waking, after school, and evening, before bed) according to age, 1.5 hours later on weekend mornings for older participants and 30 min earlier in the evenings for younger participants [66].

Gender and/or Age Adherence

The impact of gender and/or age on adherence was considered by 2 high-quality studies [60,67]. *eOuch* (n=112) reported gender or age had no effect [67]. Conversely, the *iPeer2Peer Program* reported that male participants (n=2/18) had lower adherence [60]. The 2 male participants completed 5 and 7 video calls, respectively, instead of the expected 10 as per protocol, and call length was nearly half that of female participants (12/16) [60].

Content Adherence

The most common topics raised/learning modules visited by participants in self-management programs were reported by 3 high-quality studies. The most common were *understanding arthritis* and *management issues* [60,61,65] (Multimedia Appendix 6).

Theme 2: Barriers Preventing Usability

Personal Barriers

Personal barriers preventing adherence were reported qualitatively by 6 fair to good–quality studies. The main barrier was illness, both JIA- and non-JIA-related [59-61,65,68]. In the *iPeer2Peer Program*, illness affected both the participants and peer mentors [60]. Other barriers included hospitalization [61,65], injury and pain [59], and common childhood activities such as study time/assessments [59,60,65,66,69], school trips [61], extracurricular activities [59], holidays [61,66], a party, a sports tournament [61], loss of mobile phone privileges, loss of activity tracker [59], death in the family, being too busy, weather, no babysitter for siblings [61], no longer interested [61,68], and no specific reason [61,64,68].

Technical Barriers

Technical barriers preventing adherence were reported by 7 fair to good–quality studies [59,61,63,65-67]. Barriers included log-in [61,65], software [59,66,67], hardware [59], device [59,66], and network problems [63,66,67]. This resulted in participants dropping out of the study [65] and lost data [63,67]. Future problems were eliminated through software changes, consultation with network providers, instructions on how to reset the device [66], and data back-up [66,67] ([59,61,63,65-67,69] Multimedia Appendix 7).

Device Barriers

Overall, 3 fair to good–quality studies compared electronic *eOuch* pain diary entries [66,67,69] with the paper-based pain assessment—brief pain inventory (BPI), short-form [70]. In 1 study, participants made no errors using *eOuch* compared with 90.8% (69/76) of errors using the BPI [67]. Most errors were related to how they marked the visual analog scale—77% (55/76) were confused by the order of least, average, and worst pain ratings. Participants with higher pain levels made more errors. There was no statistical difference in age (P=.51) or sex (P=.40) [67].

In another fair-quality study, 3 different devices were compared by children (aged 4-7 years), adolescents (aged 8-18 years), and parents when completing the web-based pain assessment *SUPER-KIDZ* [63]. These devices included paper, a handheld Apple iPod touch (second generation), and a computer/laptop. The study reported a significant difference in the number of missed responses by adolescents using the iPod (*P*=.047) compared with parents (*P*=.16) and children (*P*=.37) [63]. The iPod also required the most amount of time for adolescents and parents (*P*<.001), followed by computer (*P*<.001) and paper (*P*<.001). There was no significant difference in the device used by children completing a 2-item survey (*P*=.64) [63].

In the same study, children preferred the computer to paper or iPod because it was simple and fun to use (*P*=.008) [63]. Adolescents least liked the iPod because of size, unfamiliarity, and increased time to complete responses *(P*=.001). Adolescents also described paper assessments as the most inappropriate for their age group (*P*=.004) [63].

Theme 3: User Feedback

Acceptability and Satisfaction

All 7 interventions gained positive feedback from young people [59-63,65-67]. A total of 8 fair to good–quality studies reported that young people liked being physically active [59], making new friends [61], meeting someone with JIA whom they could relate to, or who had already experienced what they were going through (JIA- and non-JIA related) [60], how the intervention looked [66,67], the intervention's content [65], getting information about JIA [60], personalization through interactive features [65], and an email character called Buddy [61]. Four studies reported that young people would continue to use or recommend interventions [59,65-67]. Improvements were also suggested in exercise programs and the age range of the content [61].

Parental feedback was also considered by 2 interventions [61-63]. *Rheumates@Work*, a good-quality study, reported that parents liked the interventions (63/64, 99%) [61] and learned something (48/64, 75%) [61]. Parents also provided high evaluation scores (median 8/10, range 4-10) for *ePROfile*, reporting *ePROfile* as useful (t1=57/65, 88%; t2=37/46,80%); however, the satisfaction of parents and young people did not differ between IG and CG [62] ([59-63,65-67] Multimedia Appendix 8).

Theme 4: Cost of Delivering the Intervention

Only 1 of the 7 interventions reported the cost of establishing and maintaining the intervention [61]. *Rheumates@Work*, a good-quality study, reported on program content €10,000 (US $ 11,888); web design, language adaption for young people €1500 (US $ 1783); staff numbers (n=1-2 part-time and/or physician/psychologist) for facilitating group sessions; the time needed to monitor the participants' progress and sending emails (30 min/week); and the participants' time (1 hour/week) [61].

Overall, 4 studies reported that they provided participants with a device to enable access to the intervention [59,66,67,69]; 3 fair to good–quality studies supplied a PDA [66,67,69], and 1 fair-quality study provided a wearable accelerometer [59]. All devices were to be returned at the conclusion of the study. Only half of the participants (15/28, 55%) returned the wearable accelerometer [59]. These studies did not report on these costs, and a request for further information was unsuccessful.

Discussion

Principal Findings

To the best of our knowledge, this is the first systematic review to evaluate the usability of eHealth and mHealth interventions targeting young people living with JIA (aged 4-18 years). Guided by our 3 research questions, this review identified 7 interventions: *Misfit Flash*, *Rheumates@Work*, *iPeer2Peer Program*, *eOuch*, *ePROfile*, *SUPER-KIDZ, and Teens taking charge: managing arthritis online*. The methodological quality of the studies supporting these interventions ranged from fair [59,62,63,66,69] to good [60,61,64,65,67,68]. The dropout rate across 9 studies was low (49/634, 7.7%; mean 5, SD 6.1) [59-67].

Identification of the Digital Health Interventions

Interventions to Improve JIA Model of Care

Of the interventions, 3 allowed participants to self-report pain [63,66,67,69] or HRQoL [62]. One intervention aimed to generate a computer-based pain summary [63] Another, to improve HRQoL communication during the PR consultation [62]. This form of real-time data collection has the potential to improve data processing [71] and patient monitoring, allowing well-informed, person-centered health care decisions to be made [72].

Interventions to Improve Self-Managing Behavior

In total, 3 interventions aimed to improve self-management behavior [61,65,68] and 2 interventions aimed to improve physical activity [59,64,68]. Participants focused their educational needs on understanding arthritis and disease management issues [60,61,65]. Understanding these needs from a young person's perspective is important because there is often a difference in opinion by young people, parents, and health professionals to what self-management programs should include [34]. Research shows that by correctly strengthening a young person's personal knowledge, their motivation and competence to make well-informed health decisions improve [73], reducing their long-term health risks [29].

Usability

User Engagement

A range of promotional activities was used to facilitate the engagement of the participants with the interventions. These promotional activities are referred to in the literature as persuasive influences [74,75]. Although the studies in this review did not evaluate their effectiveness, notably other systematic reviews have reported their importance [74-76] and supported their inclusion in the intervention design to promote adherence [74]. In fact, for web-based health interventions, a combination should be used, for example, tailored interactive health information, reminders, and incentives to promote active engagement [75], and weekly website updates to increase log-ins [76].

The interventions in this review used, on average, 4 persuasive influences (range 1-7), the 2 most common being training [59-63,65] and ongoing human communication [60,61,64-66]. Other studies support the use of human communication through face-to-face segments, peer-to-peer support, a health professional, or counseling to increase website usage [74-76]. In this review, telephone contact was the most common type of human communication. *Teens taking charge: managing arthritis online* reported how the use of a coach providing telephone support improved website engagement [65]. Interestingly, this study did not employ a health professional, as other systematic reviews have suggested [75,76]. Instead, an undergraduate student studying psychology followed a standardized script to review homework and goals [65], possibly reducing the cost of the intervention.

However, not all forms of human communication identified in this review were supported. A systematic review identified 9 studies where discussion boards only provided a moderate level of peer support for young people [75]. Similarly, *Rheumates@Work* reported low engagement rates with chat sessions (17/64, 27%) [61], reinforcing the need to include young people in the design and development.

In this review, to improve the young person's experience and ensure that the interventions were achieving the intended interactions, personal barriers were removed [59-61,63-68]. Pain diary reporting times were adjusted according to age, and program schedules were flexible to cater for JIA- and non-JIA-related illnesses [59-61,65], school, and social activities [59-61,65,66]. Technical barriers were also overcome by most interventions that store their data on an external server, rather than the electronic device being used [60-62,65,66]. The privacy of health information was further maintained through secure participant accounts with restricted access [61-63,65,66]. For example, the PR could only see their own patients' results [62]. Similar measures are reflected in other studies, supporting the use of certified servers and data security, despite being costly and requiring a technical team to set up and maintain it [77,78].

User Feedback

All interventions in this review gained positive feedback from young people [59-63,65-67] and parents [61-63], although some improvements were identified [60,61,65]. *Rheumates@Work* participants, for example, requested more specific exercise programs and age-appropriate content. The targeted age range of 8 to 13 years was too broad—slightly difficult for younger participants, and too childish for older participants [61]. The transparency of the intervention content is also important because the WHO suggests that content needs to align with national guidelines or regulatory statutes; if the intervention is successful, it may be considered as a medical device [41]. Only 4 interventions in this review aligned their content with either guidelines or regulations [61,64], validated tools [62,66,67,69], a research methodology (Delphi technique) [63], and/or learning theory [61,64].

Cost Associated With the Intervention

Only 1 study in this review reported costs related to the implementation of their intervention [61], despite the WHO strongly suggesting this [48]. Costs should include long-term direct and indirect costs, starting from software development to training, implementation, and the end benefits for patients and the health care system [79]. For example, a recent systematic review of the utilization of mHealth interventions reported reduced travel time and fuel costs for health care workers and patients, and increased working time for health care workers [80]. Considering costs early, during prototype development, may help inform strategic decisions to ensure the intervention, if successful, is cost-effective, easily accessible, and sustainable when translated into the community [79].

Future Research to Consider Gender Differences

Only 3 studies in this review considered gender differences [59,60,67]. This is probably because the JIA population is predominantly female, with 3 to 6.6 females to every 1 male [81]. Although the findings were not significant, gender differences have been reported on internet use by men, women [82], and college students [83]. This indicates the need to include gender differences in future research to identify different support needs and/or gender-specific persuasive influences that could be adopted to promote adherence for young people.

Limitations

The findings of this systematic review need to be considered cautiously because of the limited number of studies included. Our methodology could have been improved by including qualitative studies in our selection criteria and individually handing searching journals relevant to digital health to ensure no usability issues were omitted and reduce publication bias from the database search.

Meta-analysis was also not possible in this review because all interventions considered different outcomes measures, depending on their stage of development. Instead, this systematic review largely relied on descriptive summaries to organize and clarify the data from formal and informal assessments. This form of analysis can be subjective; participants may have been influenced by the novelty of the intervention, boosting their engagement and feedback. There is also a risk of reporting bias by the author. To reduce this risk and improve transparency, all authors reviewed each stage of the data analysis.

The generalizability of our findings may also be limited. Participants were included in this review with other forms of rheumatic disease, or their diagnosis was unknown or not recorded (86/634, 13.6%; Table 1) [62,63,66,67]. Dissecting the results for young people, specifically living with JIA, was not possible.

This review also only focused on 3 of our 4 protocol questions: (1) identification of the intervention, (2) usability, and (4) cost, rather than (3) effectiveness, to allow us to capture a more detailed description of the interventions and usability problems faced by participants. The effectiveness of the interventions will be covered in a follow-up publication.

Conclusions

Using a narrative, descriptive methodology, our review identified 7 interventions for JIA, targeting health issues such as pain, HRQoL, physical activity, and chronic disease self-management. The usability of the interventions was facilitated through training and ongoing human communication. Engagement was promoted by a combination of persuasive influences, and barriers preventing adherence were removed through personal reminders and flexible program schedules to cater to JIA- and non-JIA illness or other activities commonly seen in childhood. The feedback obtained was that most young people and their parents liked the interventions. Although too premature to support the effectiveness of our claims, this review will add to the growing body of evidence influencing the development of future eHealth and mHealth interventions. Further research is needed to consider gender differences, associated costs, and the effectiveness of interventions on health outcomes to better support young people living with JIA.

Authors' Contributions

All authors contributed to the conceptual design, methodology, data extraction, manuscript development, and final manuscript approval.

Conflicts of Interest

None declared.

Multimedia Appendix 1
PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist.
[DOC File , 63 KB - pediatrics_v3i2e15833_app1.doc]

Multimedia Appendix 2
Search terms and database search strategy.
[DOCX File , 119 KB - pediatrics_v3i2e15833_app2.docx]

Multimedia Appendix 3
Overview of the seven eHealth and mHealth interventions for JIA.
[DOCX File , 17 KB - pediatrics_v3i2e15833_app3.docx]

Multimedia Appendix 4
Overview of the eleven eHealth and mHealth studies targeting Juvenile Idiopathic Arthritis.
[DOCX File , 26 KB - pediatrics_v3i2e15833_app4.docx]

Multimedia Appendix 5
Methodological scores of the eleven studies using the Down and Black.
[DOCX File , 16 KB - pediatrics_v3i2e15833_app5.docx]

Multimedia Appendix 6
Intervention adherence rates, including week to week, time of day and content adherence by young people with JIA.
[DOCX File , 16 KB - pediatrics_v3i2e15833_app6.docx]

Multimedia Appendix 7
Summary of the technical problems experienced by users with JIA, obstructing the adoption of the intervention.
[DOCX File , 14 KB - pediatrics_v3i2e15833_app7.docx]

Multimedia Appendix 8
User feedback: Results of Acceptability and Satisfaction questionnaires.
[DOCX File , 17 KB - pediatrics_v3i2e15833_app8.docx]

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Abbreviations

BPI: brief pain inventory
CG: control group
HRQoL: health-related quality of life
IG: intervention group
JIA: juvenile idiopathic arthritis
mHealth: mobile health
PDA: personal digital assistant
PR: pediatric rheumatologists
RCT: randomized controlled trial
WHO: World Health Organization

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Original Paper

Pediatric Asthma Action Plans: National Cross-Sectional Online Survey of Parents' Perceptions

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Abstract

Background: Asthma Action Plans (AAPs) are recommended for pediatric patients to help improve asthma control. Studies have shown variable results for unscheduled doctor and emergency room visits. AAPs may have an impact on parental self-efficacy for asthma management as well as on other daily living factors that are valuable for patients and families, such as the number of missed school days and parental workdays, and on school and caregiver management.

Objective: The purpose of this study is to understand parent perceptions of AAPs. The goals of this analysis were threefold, including examining (1) the association between pediatric AAPs and parental self-efficacy, (2) parent perceptions of the helpfulness of an AAP for daily living factors, and (3) associations with the type of provider who gave the AAP (a primary care provider or an asthma specialist).

Methods: A national cross-sectional online survey was completed in October 2018 by parents of children with asthma aged 0-17 years. Survey questions included the presence or absence of a pediatric AAP, the Bursch Parental Self-efficacy for Asthma scale, parental perceptions of the AAP's helpfulness with regard to daily living factors ranked on a 5-point Likert scale, and the provider type who gave the AAP. Survey responses were summarized in terms of percentages or means and standard deviations. A 2-sample *t* test and analysis of covariance were used to compare self-efficacy for asthma and parental-perception-of-helpfulness scores between subjects with an AAP versus subjects without an AAP. All reported *P* values were 2-sided.

Results: A total of 704 parents with a child with asthma completed the survey. The parents had a mean age of 37.5 years (SD 10.9), and 82% (577/704) were women and 18% (127/704) were men. Most (564/704, 80%) parents had an AAP for their child; 65% (367/564) were written, 51% (286/564) were online, and 84% (474/564) were available at school. The Bursch Self-efficacy scale was significantly higher for parents with an AAP (mean 57.7, SD 8.6) versus no AAP (mean 55.1, SD 9.9; *P*<.001). Parents reported that they agreed/strongly agreed that an AAP was helpful for daily living factors, including managing asthma (446/544, 82%), decreased parental missed workdays (367/544, 68%), decreased child missed-school days (396/542, 73%), and for when a child is at school (422/541 78%), with other caregivers (434/543, 80%), doing normal activities (421/540 78%), and leading a normal life (437/540 81%). Parents agreed/strongly agreed that an AAP was helpful from all provider types: a pediatric provider (583/704, 82.8%), a family practice provider (556/704, 79%), and an asthma specialist (594/704, 84.4%). There was no significant difference (*P*=.53) between the type of provider who gave the AAP.

Conclusions: Parents who had pediatric AAPs for their children reported increased parental self-efficacy compared to those who did not have AAPs. Parents found AAPs helpful for decreasing missed time from work and school, and for asthma management when at home, school, and with other caregivers. Significant AAP helpfulness was seen regardless of the provider who gave the AAP, the parent's education, and income level. Findings support the usefulness of pediatric AAPs for families and the development of easily sharable electronic AAPs for children.

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KEYWORDS

pediatric asthma; asthma action plan; parent; online survey; self-efficacy; daily living factors; parental work; school absence; school management; caregiver management; child activity; primary care provider; pediatrician; asthma specialist

Introduction

Background

Asthma is the most common chronic condition of childhood [1], affecting 7 million children in the United States [2]. Pediatric asthma can result in severe breathing distress [3], causes over a half million hospitalizations each year, and is the leading reason for hospitalization for children aged 1-17 years [4]. Further, caring for a child with asthma can lead to negative impacts on daily living for patients and families. Factors of daily living that may be negatively impacted by asthma include children missing days from school, parents missing days from work, and challenges in coordinating care with caregivers and schools [5].

To reduce health risks and quality of life impairments associated with asthma, the Centers for Disease Control and Prevention and the American Academy of Pediatrics recommend providing pediatric asthma patients with an Asthma Action Plan (AAP). An AAP is a written plan for the daily control of asthma symptoms, including steps for a family to follow if asthma symptoms develop or worsen [6,7]. The AAP may be on paper, online, or both, and can be provided to a family by a primary care provider (PCP) or an asthma specialist as part of routine asthma care. An AAP is intended to increase child and parental knowledge as well as child self-efficacy and parental self-efficacy (ie, parental perception of one’s ability to provide appropriate care) in managing the child's asthma. Parents and children are instructed about AAPs during clinic visits with older children and adolescents who are increasingly managing their symptoms independently. Thus, an AAP may lead to better control of asthma symptoms, reduce unplanned medical visits, and improve the consistency of asthma care that children receive at school and with caregivers.

Despite these potential benefits, studies measuring the impact of AAPs on asthma complications have shown variable results. Some studies have not supported that providing AAPs to children is associated with a decrease of symptom-free days, urgent care visits, or unscheduled doctor visits [8-10], while other studies on AAP use found a decrease in missed school days, emergency room use, and unscheduled doctor visits [11-13], as well as improved confidence in parents caring for children with asthma [11]. AAP effectiveness may be influenced by income and literacy. There are several factors that may create challenges for those with lower income and asthma, including access to medical care, an urban environment, and lower literacy [14]. Lower-income families are less likely to have an AAP [14] and have an increased risk for asthma treatment failure and exacerbations [15]. Low literacy has been linked to misunderstandings of AAP medications and instructions [16], as well as greater asthma severity [17]. Thus, additional research is needed to elucidate the role of AAPs in reducing asthma complications.

Pediatric asthma exacerbations can negatively impact daily living factors for pediatric patients and families. These factors may be influenced by parental asthma self-efficacy, parental perception of AAP helpfulness, and which type of provider supplies the AAP. Parental asthma self-efficacy may influence whether parents feel able to take steps at home to manage their child's asthma. Further, the perception of AAP helpfulness may influence whether parents decide to use the AAP in the event of an asthma exacerbation, and the perception may vary depending on income and college education. Finally, patients may be provided an AAP by their PCP or an asthma specialist. Referral to an asthma specialist may depend on several factors, including the PCP’s comfort level with managing asthma, the severity of asthma, and limitations of access and geography. Parents may view the AAP differently if provided in a primary-care versus specialty setting.

Objectives

The purpose of this study is to understand parent perceptions of pediatric AAPs. The goals of this analysis were threefold, including examining (1) the association between pediatric AAP provision and parental asthma self-efficacy, (2) parents' perceptions of the helpfulness of an AAP for daily living factors, and (3) associations with the type of provider who gave the AAP (PCP or asthma specialist).

Methods

In October 2018, we conducted a cross-sectional survey using a national online panel (Qualtrics; version 102018); the Institutional Board at the University of Wisconsin-Madison approved this study.

Participants and Recruitment

We recruited parents using Qualtrics. Qualtrics was chosen as the platform because surveys deployed to Qualtrics panels allow for a focus on participants meeting specific criteria. The online survey platform allowed for the identification of parents and, particularly, the oversampling of children with chronic diseases. Further, Qualtrics panels typically demonstrate demographic characteristics that fall within a 10% range of values observed in the US population [18]. Qualtrics recruits participants using online advertisements on platforms such as social media, inviting survey participants to earn credit toward rewards such as gift cards, in-application purchases, or airline miles. A background check is conducted to verify identity before the participant becomes part of a panel and eligible for recruitment.

Qualtrics sent survey invitations to existing US panel members who were English-speaking parents of children 0-17 years old in order to obtain a group consisting of 25% of parents with a child with a chronic illness. This asthma analysis was part of a larger survey of 3000 parents. The design was planned to include at least 25% of parents with children with chronic disease toward appropriate sample sizes for studies of children with and without chronic disease. A recruitment message was emailed to potentially eligible individuals notifying them of a survey opportunity, describing the estimated survey length (15 minutes), and informing them that up to $20 in e-Rewards credit could be obtained in return for participation. All participants provided informed consent. Parents who noted that their child had asthma were included in analyses.

Survey Measures

Demographic variables included age, gender identity, race, ethnicity, parental education level, household income, residential setting (rural, suburban, or urban), and geographic region (Midwest, Northeast, South, West) [19].

Asthma Action Plan Presence

Participants were asked if they had an AAP for their child. If they did, they were asked if the AAP was written, online, and available at their school ("yes" or "no"). Participants were then asked which type of provider gave the AAP to the parent. Response options included "pediatric provider," "family practice provider," "asthma specialist," or "other." Responses were mutually exclusive.

Parental Asthma Self-Efficacy

Parental asthma self-efficacy was assessed using the Bursch Parental Self-efficacy for Asthma scale [20]. This survey includes 13 questions such as "How sure are you that you would know which medications to use when your child is having a serious breathing problem?" and "How sure are you that you can help your child to prevent a serious breathing problem?" Participants provided responses using a 6-point Likert scale, from 1 = "Not at all sure" to 5 = "Completely sure" and 6 = "Does not apply," per the Bursch Parental Self-efficacy scale protocol. The total score ranged from 13 to 65, with a higher score indicating a higher level of self-efficacy.

Parent Perceptions of Helpfulness of the AAP for Daily Living Factors

Participants were asked to indicate their perceptions of the AAP with regard to its helpfulness for daily living factors by indicating their agreement with a series of statements. These included a general statement, "the Asthma Action Plan has been helpful for managing my child's asthma," as well as statements for specific factors, such as "the Asthma Action Plan decreases the number of days that I miss work due to my child's asthma," "the Asthma Action Plan decreases the days that my child misses school due to asthma," "the Asthma Action Plan is helpful for when my child is at school," and "the Asthma Action Plan is helpful when my child is with another caregiver." Responses used a 5-point Likert scale, which ranged from 1 = "Strongly disagree" to 5 = "Strongly agree."

Analysis

Descriptive analyses were summarized in terms of means and standard deviations or proportions. For the helpfulness of daily living factors, results were combined to report on the proportion who agreed or strongly agreed and summarized in terms of frequencies and percentages. A 2-sample *t* test was used to compare self-efficacy for asthma and parental-perceptions-of-helpfulness scores between subjects with an AAP versus subjects without an AAP. An analysis of covariance (ANCOVA) was conducted to adjust for comparison by parents' age, gender, education, household income, and provider type. All reported *P* values were 2-sided, and *P*<.05 was used to define statistical significance. Statistical analyses were conducted using SAS software (version 9.4; SAS Institute).

Results

Participants

A total of 704 parents reported having a child with asthma and completed the survey. Participants had a mean age of 37.5 (SD 10.9) years; 82.1% (578/704) were women and 17.9% (126/704) were men; 65% (458/704) had a college degree. The majority of participants (429/704, 61%) had an income below the national median (<$75,000), and 68.2% (480/704) lived in suburban or urban settings. Table 1 displays demographic data.

Table 1. Demographic data of the parent participants (n=704).

Participant characteristics	Values, n (%)
Gender	
Male	122 (17.4)
Female	575 (82.1)
Race	
White	546 (77.5)
Hispanic	111 (15.9)
Black	80 (11.4)
Asian	21 (2.9)
American Indian	15 (2.1)
Native Hawaiian	7 (1.0)
Multiracial	24 (3.4)
Education	
No college degree	238 (34)
College degree	464 (65)
Household income	
<$75,000	431 (61)
>$75,000	272 (39)
Residential setting	
Rural	223 (31.9)
Suburban	291 (41.6)
Urban	186 (26.6)
Geographic region	
Midwest	163 (23.8)
Northeast	135 (19.7)
South	264 (38.5)
West	124 (18.1)

Asthma Action Plan Presence

Most participants (564/704, 80%) reported that they had an AAP for their child. AAPs were available to 65% (367/564) of participants in written form and 51% (288/564) online. Most participants (474/564, 84%) reported that the AAP was available at school.

Association of AAP with Parental Asthma Self-Efficacy

Parental asthma self-efficacy was significantly higher for parents with an AAP (mean 57.7, SD 8.6) compared to parents who did not have an AAP (mean 55.1, SD 9.9, *P*<.001). After adjusting for parents' age, education, household income, gender, and provider type, the adjusted mean for parents with an AAP was 58.3 (95% CI 52.2-64.4) versus 54.8 (95% CI 48.7-60.9) for parents without an AAP (p=0.0005).

Helpfulness of the AAP for Daily Living Factors

Among the 564 parents who had an AAP, 82% (462/564) agreed or strongly agreed with the general statement, "the Asthma Action Plan has been helpful in managing my child's asthma." Most parents agreed or strongly agreed that having an AAP was helpful for individual daily living factors, including the management of asthma (446/544, 82%), decreased parental missed workdays (367/544, 68%), decreased child missed school days (396/542, 73%), and for times when the child is at school (422/541, 78%), with other caregivers (434/543, 80%), doing normal activities (421/540, 78%), and leading a normal life (437/540, 81%). Table 2 shows the participant ratings of the helpfulness of the AAP.

Table 2. Participant ratings of the helpfulness of Asthma Action Plans (AAPs).

Asthma management factors	N	Mean agreement rating[a] of AAP helpfulness, Mean (SD)
Management of the child’s asthma	544	4.2 (0.9)
Comfort with managing the child’s asthma	541	4.2 (0.9)
Decrease in parental missed workdays	544	3.9 (1.1)
School asthma management	541	4.1 (1.0)
Decrease in the child’s missed school days	542	4.0 (1.0)
Caregiver asthma management	543	4.2 (0.9)
Ability for the child to have normal activity	540	4.1 (1.0)
Ability for the child to lead a normal life	540	4.1 (0.3)

[a] A Likert scale was used, ranging from 1=“Strong disagree” to 5=“Strong agree.”

Helpfulness of the AAP and Provider Type, Household Income, and Education

The proportion of participants who reported agreement/strong agreement for the question “The Asthma Action Plan has been helpful in managing my child’s asthma” were compared between provider type (pediatric provider, family practice provider, and asthma specialist), household income (≥$75,000 versus <$75,000), and education level (college education versus no college education). There was no significant difference (*P*=.53) observed in the rates of participants who reported agreement/strong agreement for the question “The Asthma Action Plan has been helpful in managing my child’s asthma” when comparing between provider types: 83% (583/704) for a pediatric provider, 79% (556/704) for a family practice provider, and 84% (594/705) for an asthma specialist. For participants with a household income of ≥$75,000, the rate of participants who agreed/strongly agreed with the question “The Asthma Action Plan has been helpful in managing my child’s asthma” was 85% (598/704), as compared to 80% (563/704) for participants with a household income of <$75,000 (*P*=.20). Furthermore, there was no significant difference (*P*=.48) detected in the rates of participants who reported agreement/strong agreement with the question “The Asthma Action Plan has been helpful in managing my child’s asthma” between participants with a college degree or above (570/704, 81%) versus participants without a college degree (591/704, 84%). Table 3 displays the logistic regression analysis results for the prediction of whether the AAP is helpful at managing asthma.

Table 3. Results of the logistic regression analysis for predicting whether an Asthma Action Plan (AAP) is helpful for managing asthma.

Participant variable	Rate of respondents who answered “agree” or “strongly agree” to the question “AAP is helpful at managing my child’s asthma,“ % (95% CI)	Odds ratio (95% CI)	*P* value
Provider who gave AAP			.53
Pediatrics	82.8 (78.2%-87.3%)	0.89 (0.46-1.69)	.72
Family practice	79.0 (72.4%-85.6%)	0.69 (0.34-1.41)	.30
Asthma specialist	84.4 (76.5%-92.2%)	Reference	
Household income			
≥ $75,000	84.5 (79.1%-90.0%)	1.41 (0.83-2.40)	.20
< $75,000	79.6 (74.2%-85.0%)	Reference	
Parent education			
College degree	80.7 (74.5%-86.8%)	0.82 (0.48-1.42)	.48
No college degree	83.5 (78.6%-88.3%)	Reference	

Discussion

Principal Findings

This study sought to understand associations of pediatric AAP provision with parental self-efficacy for asthma, perceptions of the AAP’s helpfulness for managing daily living factors for families, and whether the helpfulness of the AAP differed based on the type of provider who gave the plan. We found that parents who had an AAP had higher parental self-efficacy than parents who did not have an AAP, and that most parents viewed the AAP as helpful for many daily living factors. Further, there was no difference in parental perceptions of AAP helpfulness, whether provided by a PCP or asthma specialist.

Our first finding was that parents who had AAPs had slightly, but statistically significant, higher asthma parental self-efficacy than parents who did not have AAPs. Our finding is consistent with a recent study suggesting that AAP use is associated with improved confidence for parents caring for children with asthma

[11]. The asthma self-efficacy questions included measures for comfortableness for, understanding of, and feelings of the ability to care for a child's asthma symptoms, which can contribute to confidence. Taken together, these studies support that AAPs can lead to (in the very least, small) improvements in parents' abilities to care for their children with asthma. Of note, all our participants, both with and without an AAP, had high mean scores, so there may have been a ceiling effect. As the surveyed parent population participated in the study via the Qualtrics format, they had access to, and the ability to use, the internet, and they may have used the internet to access supportive health information. Thus, they may have higher self-efficacy than parents who are not able to use or do not have internet access. Further investigation of AAP experiences among parents with limits on internet use or access is warranted.

Our second finding was that most parents perceived the AAP to help daily living factors, regardless of income and education. Parents perceived that AAP use helped decrease their time missed from work and their child's time missed from school due to asthma. This contrasts with a finding in which parents who used AAPs did not report a significant decrease of child symptom-free days compared to parents who did not use an AAP; those authors considered that perhaps AAP users have more symptoms and, thus, worse outcomes [8]. However, another study found that AAP use was associated with reduced school absence days due to asthma [11]. Our findings of parents' perceptions of a decreased need for work absences and school absences is consistent with this; it may indicate that AAP use decreased the severity of symptoms in at least some children, such that time away from work and school were reduced. Overall, this analysis of parent perceptions of AAP helpfulness for daily living factors supports that parents perceive benefits from having a plan and a sense of control for managing their child's asthma. Areas that involve an easing of child care, such as management during school time and time with caregivers, may be important to maintaining regular daily activities. AAPs may be useful for others beyond parents, helping teachers, school personnel, and other caregivers during school, daycare, and after-school activity hours. Further studies directly assessing asthma control and AAP use by parents, school personnel, and caregivers would be valuable.

Finally, a high percentage of parents reported the AAP to be helpful regardless of the provider who distributed the plan. These findings were consistent even with adjustments for income and education. This result implies that an AAP can be a beneficial tool for children with asthma when distributed through an asthma specialist or primary care provider for the management of childhood asthma.

Limitations

A limitation of this analysis is that the survey was conducted online and for English-speaking participants. Therefore, families who do not have internet access or are non-English–speaking are not represented. Future studies are needed for these populations. Survey response options for providers who gave AAPs were mutually exclusive; there may have been parents who received an AAP both from their PCP and specialist. If parents received an AAP from both sources, this may have influenced their self-efficacy and feeling of helpfulness. Further, participants were asked about their perceptions of the AAP's helpfulness rather than the number of actual missed school days and workdays; measures of helpfulness were not validated, and asthma control and AAP use were not measured with validated instruments. However, parents' perceptions of not missing work and school may still offer a relevant measure of a sense of disruption due to asthma. Future studies could consider examining whether parents with higher parental self-efficacy and increased confidence in their child's asthma care are associated with a decrease in measured office visits and sick days off school. Direct, quantified measurement of asthma control and AAP by specified users could also be evaluated.

Conclusions

Overall, this study supports the use of AAPs as a valuable tool associated with numerous practical daily benefits that improve the management of pediatric asthma. Further, these benefits were consistently reported across parents who received AAPs from different provider types and who had varied socioeconomic backgrounds. These findings reinforce the recommendations of the Centers for Disease Control and Prevention and the American Academy of Pediatrics to provide AAPs to children. AAPs should be offered as standard asthma care for children by all providers. Technology advancements can be used to further improve asthma control for children, such as online or app-based AAPs. The development and promotion of easily sharable AAPs with school nurses, coaches, and caregivers through laptops and cell phones would help eliminate barriers for families and children with asthma from fully participating in and enjoying school, family, and childhood activities.

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Conflicts of Interest

None declared.

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Abbreviations

AAP: Asthma Action Plan
PCP: primary care provider

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Original Paper

An Interactive Smartphone App, Nenne Navi, for Improving Children’s Sleep: Pilot Usability Study

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Abstract

Background: Healthy sleep is important not only for physical health but also for brain development in children. Several reports have revealed that Japanese adults and children have later bedtimes and shorter sleep durations compared with those in other countries, possibly because of Japanese culture and lifestyles. Therefore, an intervention tool that is suitable to the Japanese sociocultural environment is urgently needed to improve children’s sleep problems in their early years.

Objective: To provide appropriate sleep health literacy to caregivers and change their parenting behavior, we developed a smartphone app that allows reciprocal interaction between caregivers and pediatric sleep experts. This paper describes a preliminary study to examine the app’s basic design and functions and to establish its acceptability and usability in a small sample.

Methods: A total of 10 caregivers and 10 infants (aged 18-28 months; 4/10, 40% boys) living in Japan participated in the study. At the start of the trial, the e-learning content regarding sleep health literacy was delivered via a smartphone. Thereafter, caregivers manually inputted recorded data about their own and their infant’s sleep habits for 8 consecutive days per month for 2 months. After pediatric sleep experts retrieved this information from the Osaka University server, they specified the problems and provided multiple sleep habit improvement suggestions to caregivers. Caregivers then selected one of the feasible pieces of advice to practice and reported their child’s sleep-related behaviors via the app. Actigraphy was used to monitor children’s sleep behaviors objectively. The concordance between the information provided by caregivers and the actigraphy data was assessed. The acceptability and usability of the app were evaluated using self-report questionnaires completed by caregivers; qualitative feedback was obtained via semistructured interviews after the intervention.

Results: There was no significant difference between the information provided by the caregivers and the actigraphy data for bedtimes and wake-up times ($P=.13$ to $P=.97$). However, there was a difference between the actigraphy data and the caregivers’ reports of nighttime sleep duration and nighttime awakenings ($P<.001$ each), similar to prior findings. User feedback showed that 6 and 5 of the 10 caregivers rated the app easy to understand and easy to continue to use, respectively. Additionally, 6 of the 10 caregivers rated the app’s operativity as satisfactory. Although this was a short-term trial, children’s sleep habits, caregivers’ sleep health consciousness, and parenting behaviors improved to some extent.

Conclusions: The present findings suggest that the app can easily be used and is acceptable by Japanese caregivers. Given the user feedback, the app has the potential to improve children’s sleep habits by sending individualized advice that fits families’ backgrounds and home lives. Further studies are needed to confirm the efficacy of the app and facilitate social implementation.

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KEYWORDS

infant sleep; app; mHealth; behavioral intervention; sleep health, PDCA cycle

Introduction

Sleep Problems in Childhood

Sleep problems in children is one of the most common caregiver concerns, regardless of cultural origins [1-3]. Previous research has shown that a good quantity of high-quality sleep during early childhood is crucial for later development [4]. For example, shorter sleep duration during the first 3 years of life has been identified as a risk factor for hyperactivity and lower cognitive performance in later childhood [5,6]. Additionally, children's sleep problems are associated with parental stress [7] and maternal depressive symptoms [8].

Sleep specialists, including pediatricians and psychologists, have long been responsible for educating caregivers of infants with sleep problems, such as sleep-onset insomnia and night waking, in pediatric sleep clinics.

Sleep Problems in Families and Impact on Children's Sleep

In a previous study comparing sleep habits and problems in 16 countries [9], Japanese children were found to have the shortest sleep times. More recently, using a validated questionnaire developed for screening children's sleep problems and the sleep-related lifestyles in Japanese families [10-12], researchers found that the mean sleep time in Japanese preschoolers was as short as 9.7 hours. Interestingly, 55% of caregivers whose children slept less than 9 hours believed that their children had good sleep [13]. Furthermore, children's sleep time was found to be strongly affected by their families' lifestyles, including watching television near bedtime and being out after 8:00 PM.

Several reports revealed that Japanese adults also have shorter sleep times [14,15], probably due to Japanese cultural notions that value hard work over sleep. These findings highlight both children's shorter sleep times and caregivers' low awareness of the issues involved. Given the known consequences of insufficient sleep for children and parents, there is an urgent need to develop an intervention for improving caregivers' lifestyles in order to positively impact children's sleep habits in the early years while also considering sociocultural factors, such as increasing dual-income and nuclear families, and Japanese sleep-related cultural factors, such as co-sleeping habits.

In Japan, parenting guidance for caregivers has traditionally been provided on a face-to-face basis during children's regular checkups at regional public health centers [16]. However, sleep problems are often overlooked at these checkups because of a paucity of sleep specialists. Even if these problems are addressed, it is difficult for caregivers to visit public health centers for repeated consultations and follow-up, as double-income families now account for the majority of the Japanese population. It is difficult to deliver appropriate sleep hygiene information to caregivers because of their lack of adequate sleep literacy, poor motivation to make behavioral changes, or difficulty identifying improvements that they can apply in their own homes.

Sadeh et al [2] suggested a transactional model that emphasizes the ongoing bidirectional links between parenting and infant sleep, such as parental, infant, intrinsic, and sociocultural factors, among others. Besides the changes in Japanese families' lifestyles, children's sleep environments have also been worsening considerably in recent years. Smartphones are very popular, and infants' exposure to such media is a major issue affecting sleep hygiene [17,18].

Some studies have examined online or mobile health education or interventions for infants' sleep [19-21]. However, interactive interventions could be more effective, given the variance in families' socioeconomic status, bedroom environments, and caregiver beliefs regarding sleep. Sviggum et al [22] showed that early, customized guidance for caregivers that focuses on revealing and acknowledging their experiences of sleep problems in their children is essential in helping caregivers cope with such challenges. Recent findings suggest that parental factors both predict and are predicted by behavioral interventions for infant sleep problems [23]. To improve children's sleep habits effectively, individualized care is desirable, such as care supported by an interactive plan-do-check-act (PDCA) cycle for caregivers.

Against this background, we developed a smartphone app that facilitates interaction between caregivers and pediatric sleep experts to improve infants' sleep habits in Japan. Using the app, caregivers reported their children's sleep and sleep-related schedules for 8 consecutive days in a month, and the sleep team provided various types of advice after analyzing the children's sleep habits. Educational content was also delivered via smartphone. Recent reviews have highlighted the need for further evaluation of mobile health interventions in children [24,25].

The aim of the present study was to describe the app's developmental design; check the system's operation, acceptability, and usability; and determine the overall potential of the app to change infants' sleep habits or parental cognition and behavior via user feedback in a small trial.

A Priori Hypotheses

We hypothesize that the app would work well and with little discomfort for Japanese caregivers, since its concept and design required minimal effort. We also predict that the caregivers' input information regarding sleep-related habits will be reliable compared with the data from the actigraph.

Methods

Ethics Approval and Consent to Participate

This study was approved by the Osaka University Clinical Research Review Committee (CRB5180007) on January 23, 2017, prior to the start of the study. All study procedures were conducted in accordance with the ethical standards of the Declaration of Helsinki. Written consent was obtained from all participants on an individual basis. All participants received a coupon for books valued at US $20 upon completion of the trial.

Participants

The study targeted only caregivers with infants aged 18 to 36 months, as the app was designed for this age group. A total of 10 participants and 10 infants were recruited from the university community over a 2-week period using a bulletin board in the nursery. The inclusion criteria were as follows: (1) fluency in Japanese, (2) possession of a mobile device (iOS or Android) with internet access, and (3) willingness to install the Nenne Navi app on the mobile device. Supported devices included the iPhone, iPad, and iPod touch with iOS 8.0 or later and Android devices with Android OS 4.3 or later.

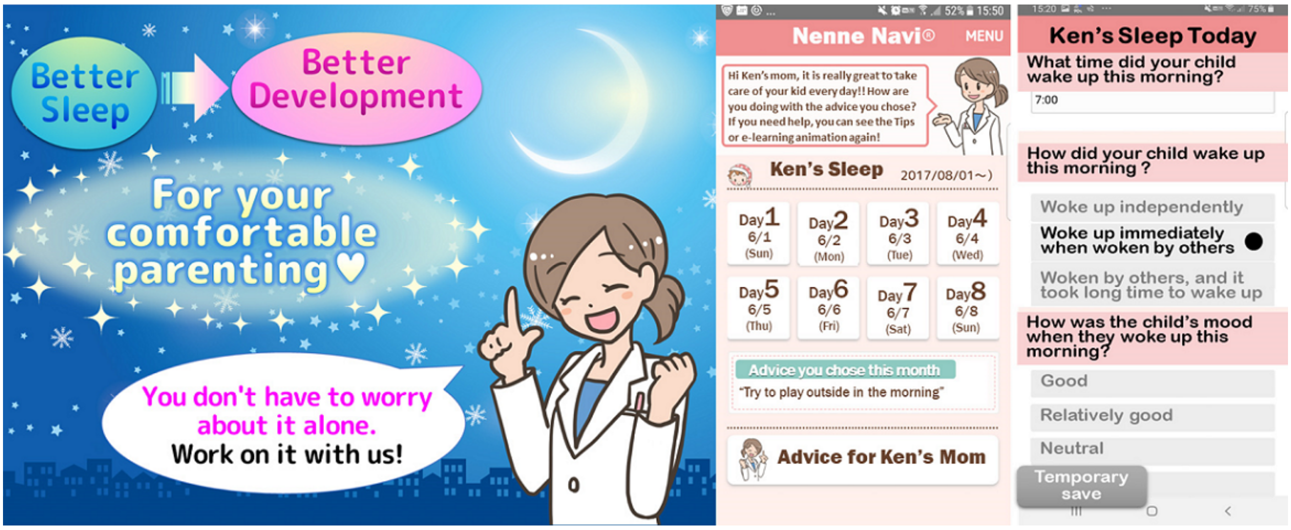
The ratio of iOS (all iPhones) to Android devices was 6:4. The mean age of the infants was 22.6 months (range 18-28 months; 4/10, 40% boys). The mean age of the caregivers (8 mothers and 2 fathers) was 36.1 years (range 31-41 years), and the ratio of family care (children at home) to professional childcare was 2:8. A total of 7 caregivers worked at Osaka University (4 medical professionals, 1 medical research assistant, and 2 office workers), and 1 caregiver was a graduate student. One caregiver was a homemaker. One caregiver (medical professional) was from another Asian country, had lived in Japan for several years, and had sufficient Japanese communication skills for participation.

Measures

App: Nenne Navi

The app, Nenne Navi, was developed by pediatric sleep experts at the pediatric sleep clinic at Osaka University Hospital. The system design was outsourced to a domestic information technology company. The Japanese word *nenne* means “sleep.” The e-learning content regarding sleep health education was delivered via narrated animations. The narrated animation lasted for 3 minutes and included the following: (1) tips for better ways to spend time during the day to ensure good sleep and (2) tips on how to spend time in the evening and nighttime to ensure good sleep. In the animation, a professional character describes the daily activities of 2 boys (a good sleeper, Taro, and a poor sleeper, Jiro; Figure 1).

Figure 1. Nenne Navi screenshots, including the page used to enter lifestyle information and provide users with messages and advice from pediatric sleep experts and the page for data input.



Hi Ken’s mom, it is really great to take care of your kid every day!! How are you doing with the advice you chose? If you need help, you can see the Tips or e-learning animation again!

Ken’s Sleep 2017/08/01~)

Day1 6/1 (Sun)	Day2 6/2 (Mon)	Day3 6/3 (Tue)	Day4 6/4 (Wed)
Day5 6/5 (Thu)	Day6 6/6 (Fri)	Day7 6/7 (Sat)	Day8 6/8 (Sun)

Advice you chose this month
“Try to play outside in the morning”

Advice for Ken’s Mom

Ken’s Sleep Today

What time did your child wake up this morning?
7:00

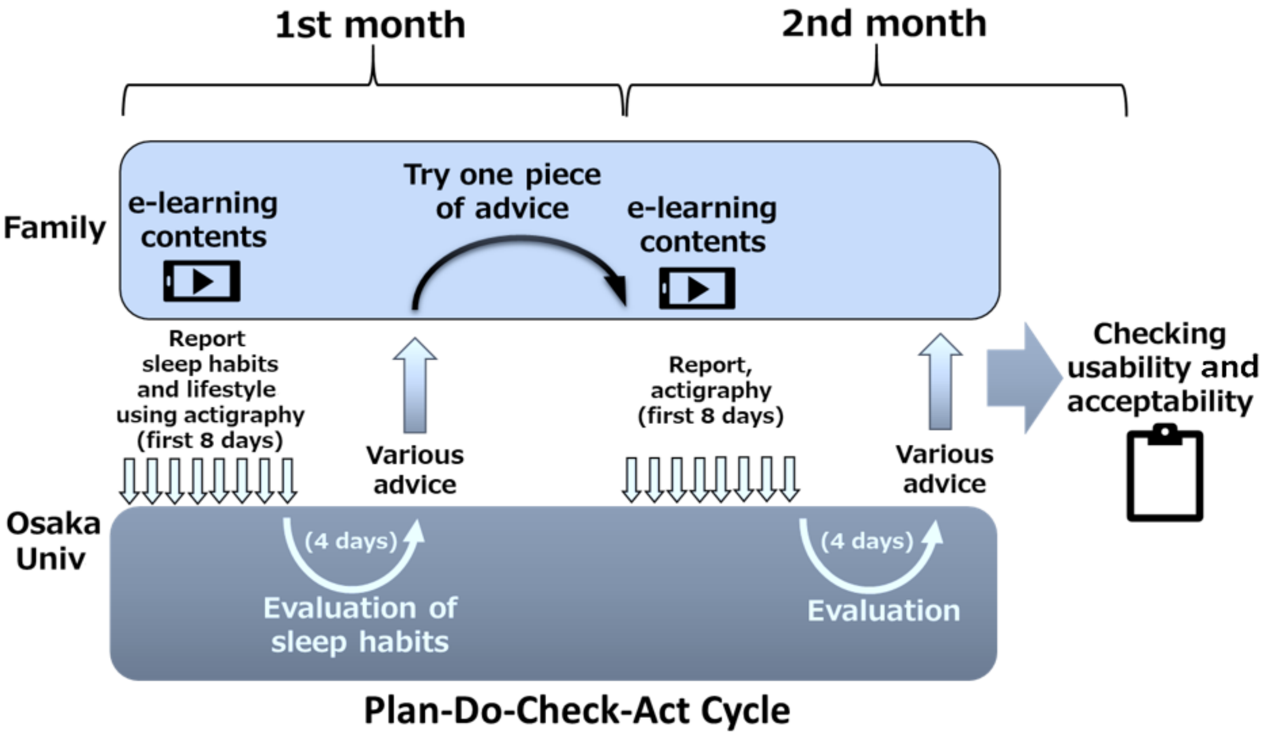
How did your child wake up this morning ?
Woke up independently
Woke up immediately when woken by others ●
Woken by others, and it took long time to wake up

How was the child’s mood when they woke up this morning?
Good
Relatively good
Neutral

Temporary save

The caregivers’ input information regarding sleep-related habits included waking time, nap time, bedtime, screen time, outdoor activity time, bathing time, dinner time, how time was spent before retiring to bed, and sleep latency (see Multimedia Appendix 1 for details) for their infants for 8 consecutive days in a month (Figure 1). They also inputted information about their own sleep and wake times, as well as their stress levels and feelings about parental care. Participants continued the PDCA cycle shown in Figure 2.

Figure 2. Plan-do-check-act cycle to improve children's sleep habits via the interactive app Nenne Navi. Univ: university.



All the input data were sent to the Osaka University virtual server hosting service developed at Cybermedia Center, Osaka University, which is equipped with network security measures such as access restrictions, encrypted communication, monitoring of unauthorized access, and backup to withstand cyber attacks. The system configuration was as follows: (1) Ubuntu 18+ Apache 2.7, (2) PHP 7, and (3) PostgreSQL 9.

The registration number of the trademark (606435 Nenne Navi, Osaka University; Taniike M, Mohri I, Aoi Y, Yoshizaki A) was registered on July 20, 2018. The patent application number was 2017-202916.

Strategy for Intervention: Individualized Small Steps, Autonomous Choice of Behavioral Experiment, and Encouragement to Support Motivation

The pediatric sleep expert team consisted of 3 pediatricians and 2 psychologists who analyzed the information entered by the caregivers and sent various types of practical advice to each caregiver. The app was designed to set personalized goals in accordance with individual users' home lives; for example, the app sent personalized advice such as “Try to have dinner before 8:00 PM” instead of “Try to have dinner earlier” to deliver specific and optimal goals to caregivers in small steps, based on behavioral therapy concepts. The app did not intend to instruct caregivers to obey the advice. Rather, it was designed to send various pieces of advice (suggestions), from which caregivers could choose one suggestion. We expected that if caregivers chose one suggestion, thinking they would try it for a while without much effort, they would try the app and follow the advice willingly.

Advice categories, which comprised approximately 60 suggestions, included how to spend time before going to bed, how to spend time in the bedroom, establishing a regular sleep rhythm, increasing daytime activity, fixing nap schedules, and fixing dinner and bathing times. Participants were asked to indicate, using the app, which suggestion they chose to try so that the pediatric sleep experts could check their degree of compliance with the advice (Figure 2). At the same time, a feedback message was sent to each caregiver (approximately 200-300 letters in Japanese) through the app. We intended to provide positive feedback on the improvement of lifestyle habits compared with the previous month, empowering caregivers and supporting their motivation.

Actigraphy

To collect objective data regarding children’s sleep and check the accuracy of the data input by caregivers, the children’s activity levels were measured using an actigraph (MTB-220; Acos Co Ltd) during the data input period (from days 1 to 8 in the first and second months). The actigraph used was modified to be connectable to the smartphone via Bluetooth instead of FeliCa. This actigraph is a small and light (weight of 9 g) coin-shaped device (external dimensions of 27 mm in diameter and 9.8 mm in depth, including clip) that records amount of physical activity by using an internal 3-axis accelerometer. Every 0.125 seconds, the number of times that acceleration exceeds a reference value is summed, and the value is recorded as the activity value over 2-minute bins. The activity intensity is calculated from the activity value as a value from 0 to 63 (64 levels). An activity intensity of 0 means the participant did not move, and larger values indicate higher levels of activity. The caregivers could attach the actigraph to their infant’s clothes with the clip on the back of the device. Caregivers were asked to press the relevant button on the app to send the actigraph data to the Osaka University server.

Questionnaires and Interviews

After the trial, a questionnaire was administered and semistructured interviews regarding the usability and operability of the app were conducted individually to collect information for system improvement. The questionnaire consisted of the following items: ease of continuation of the app, easiness of understanding the app, changes in the child's sleep habits after using the app, changes in the child's daytime behavior after using the app, and changes in the easiness of putting the child to sleep after using the app. Responses were provided using 5-point scales (5=satisfied, 4=moderately satisfied, 3=neutral, 2=moderately dissatisfied, 1=dissatisfied) and free-text comments. In the interviews, participants were also asked what motivated their continued use, their impressions of the e-learning content and advice, and how the app system could be improved. To check the feasibility of the app, we asked participants to report that if they had followed the advice.

Data Analysis

Actigraphy data were sent to the Osaka University server described above and was read by the program Sleep Sign Act (Kissei Comtec Co). After the extraction of CSV data, we determined the wake and sleep times manually using the method described by Nakasaki et al [26]. Briefly, a five-dimensional linear model was hypothesized that uses activity intensity at an evaluation epoch, as well as at two epochs before and two epochs after (total of 10 minutes). Using the activity intensity at 4 minutes and 2 minutes before the evaluation epoch, at the evaluation epoch, and at 2 minutes and 4 minutes after the epoch ($x_{-2}, x_{-1}, x, x_{+1}, x_{+2}$), each with a weighting coefficient ($\alpha_{-2}, \alpha_{-1}, \alpha, \alpha_{+1}, \alpha_{+2}$), we can determine z:

$$z = (0.24669)x_{-2} + (0.2562)x_{-1} + (0.408771)x + (0.155046)x_{+1} + (0.136728)x_{+2}$$

Here, $z \geq 1$ denotes wake and $z<1$ denotes sleep.

To compare the number of caregiver-reported nighttime awakenings (defined as those lasting for more than roughly 5 minutes) in the app with those reported by the actigraphy device, we extracted the number of events of wakefulness for 6 minutes or more from the actigraphy data. For the data entered via the app, nighttime sleep was calculated by subtracting sleep latency from the duration of time from bedtime to wake-up. For each value relating to sleep habits and sleep-related lifestyles, the mean, standard deviation, and basic statistics of each participant were calculated for both the app data and the actigraphy data.

To check the reliability of the data caregivers entered via the app, a 2-tailed paired-samples *t* test was used to compare the differences between the actigraphy data and the data entered by caregivers via the app to record children's sleep habits (ie, bedtime, wake-up time, nighttime sleep, and waking at night). The differences between sleep time duration, mean bedtime, and night awakenings for the first and second months were also assessed (using 2-tailed paired *t* tests). Analyses of these sleep habits were conducted separately for weekdays and weekends, since there could be differences in lifestyle, considering most of the caregivers worked on weekdays. To calculate the correlation value between data entered by the caregivers and actigraphy data for sleep-wake rhythms, the Pearson correlation coefficient was used. Data analysis was performed using IBM SPSS Statistics (v 26.0; IBM Corp).

Results

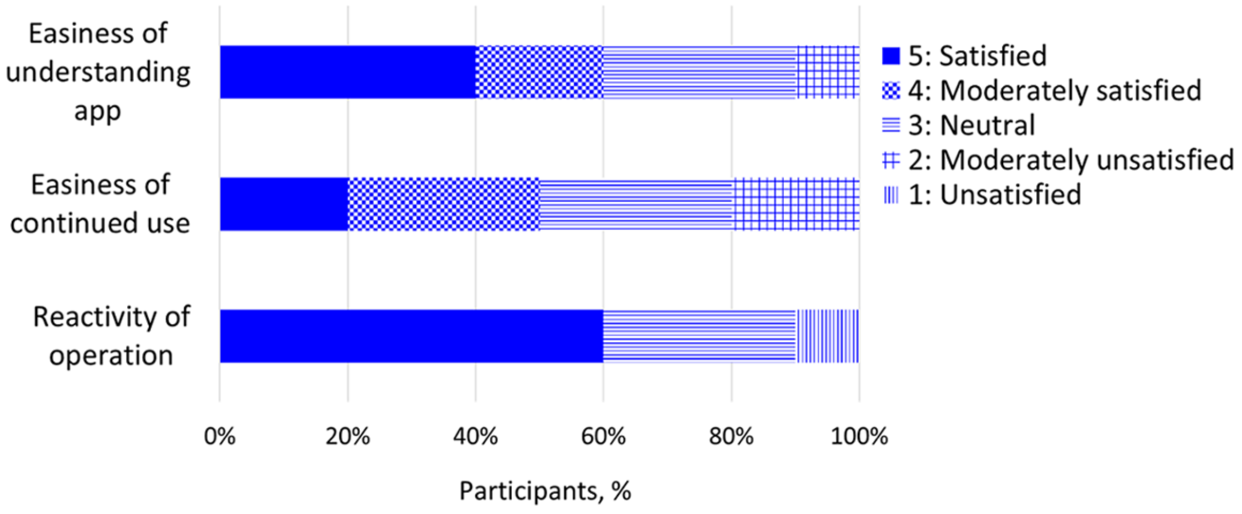
Safety in Use

All 10 caregivers completed the 2-month trial use of the app. No major problems, such as connection errors, were reported. One caregiver discontinued the use of the actigraph because of their fear of accidental ingestion. One participant was excluded from the data analysis for sleep habits because the child was using medication that could have affected sleep during the second month of the study period.

Usability of Nenne Navi

The results of the questionnaire regarding usability and operability showed that only 1 out of 10 caregivers rated the app as unsatisfactory; 6 and 5 of the 10 caregivers rated it as easy to understand and easy to continue to use, respectively. In addition, 6 out of 10 caregivers indicated that they were satisfied in the reactivity of the app's operation (Figure 3). One caregiver who was unsatisfied with the responsiveness of the app's operation reported that the screen froze repeatedly; however, the caregiver was able to continue to use the app throughout the trial after restarting the smartphone once. The results of the interviews with caregivers informed functional improvements, such as the addition of a button to save data temporarily.

Figure 3. Participants' feedback regarding the usability of the app.



Feasibility of Interactive Advice

The advice sent to caregivers by the pediatric sleep expert team consisted of various types of advice concerning children's daily lives, including increasing daytime activities, controlling media exposure, changing nap schedules, and changing ways to spend time at bedtime. When providing advice to caregivers, the expert team presented goals as clearly as possible (eg, "When your child has a nap, try to wake them before 3:00 PM"). The rate at which caregivers attempted to follow advice (ie, were able to perform advised behavior) was 76.8%.

Reliability of the Data Entered on the App

To check the reliability of the data entered by the caregivers, we analyzed the difference between entered data and actigraphy data. As shown in Table 1, there was no significant difference between the data entered by the caregivers and the actigraphy data for bedtime and wake-up time (Figures 4 and 5). However, although the caregivers correctly reported the bedtime of their children (R^2=0.676; *r*=0.822; *P*<.001), the reported wake-up time was less precise than the bedtime (R^2=0.195; *r*=0.442; *P*<.001). In addition, the duration of children's sleep was found to be significantly shorter in the actigraphy data (approximately 2 hours on average), as the number of night awakenings was significantly higher than that reported by caregivers.

Table 1. Children's sleep habits according to actigraphy and entered data by caregivers.

Measure and month	Participants, n	Actigraphy, mean (SD)	Entered, mean (SD)	*t* test (*df*)	*P* value
Bedtime					
1	10	9:05 PM (0:37)	8:58 PM (0:36)	1.62 (9)	.14
2	9	9:07 PM (0:42)	8:58 PM (0:43)	1.70 (8)	.13
Wake-up time					
1	10	6:30 AM (0:19)	6:29 AM (0:44)	0.08 (9)	.94
2	9	6:35 AM (0:31)	6:35 AM (0:38)	–0.04 (8)	.97
Nighttime sleep (min)					
1	10	432 (68.61)	548 (72.88)	–7.06 (9)	<.001
2	9	433 (62.80)	556 (78.48)	–8.20 (8)	<.001
Nighttime awakenings (times)					
1	10	9.02 (2.78)	0.41 (0.67)	10.13 (9)	<.001
2	9	8.83 (2.73)	0.47 (0.55)	9.56 (8)	<.001

Figure 4. Scatter diagram for the entered data and actigraphy data for bedtimes.

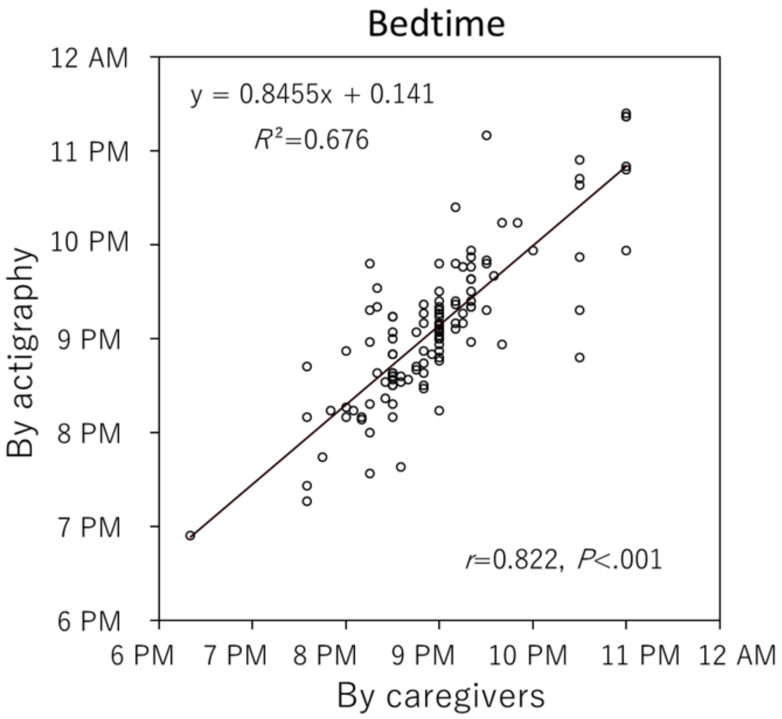
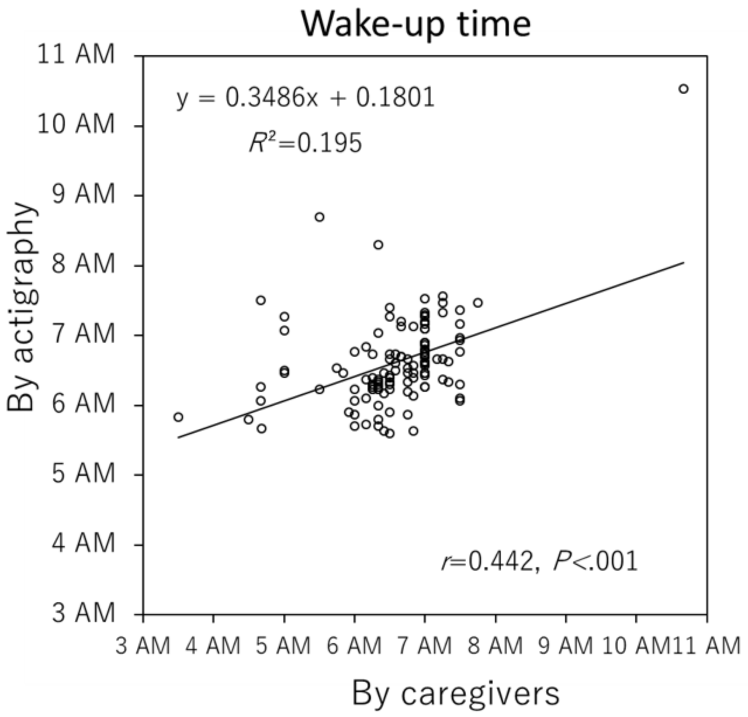


Figure 5. Scatter diagram for the entered data and actigraphy data for wake-up times.



Caregivers' Perceptions of the Effectiveness of the App

According to the results of the interviews conducted after the trial, positive changes were reported in all cases, and no caregivers reported worse sleep habits or childcare burden with the use of the app. The caregivers' reports regarding the efficacy of the app are shown in Table 2. Overall, the interactive function of the app was evaluated positively by caregivers, as shown in statements such as "It was great that I could receive advice that fit my infant and family." In addition to the positive feedback, infants' sleep time was longer on weekends (paired *t* test, *P*=.02), and bathing was finished ahead of schedule on the weekends, but the result was not significant (Multimedia Appendix 2).

A mother reported that her infant showed greater interest in various aspects of the natural world, such as birds and grass.

Table 2. Caregivers' perceived effectiveness of the app.

Perceived effectiveness of the app	Example of feedback by caregivers	Participants, n[a]
Changes in caregivers' awareness of time	- Began to think "Let my child go to bed earlier" - Began to be more aware of time in daily life	7
Changes in parenting behavior related to sleep habits	- Limiting nighttime media use - Creating positive bedtime routines preferred by their infants (eg, reading picture books) - Attempting to let their infant go to bed earlier	8
Improvement of infants' sleep-related behavior	- "My child started going to bed more willingly and earlier than before" - "My child began to fall asleep sooner after going to bed"	4
Cessation of nighttime awakenings	- "My child has fewer nighttime awakenings than before"	2
Perceived reduction of childcare burden	- "It became more comfortable to take care of my infant since they sleep better than before" - "When my infant's sleep got better, their behavior got better"	4

[a] Out of 10 participants.

Discussion

Main Findings

This pilot trial showed that there were no major problems with the system and the usability and acceptability of the app. High user dropout rates is one of the main issues of remote sleep interventions delivered via the internet and apps; results of one review study indicated a mean dropout rate as high as 78% for 5- to 6-week interventions [27]. These data showed that no participant dropped out during the 2 months of the trial. This might have occurred because (1) we included a convenience sample from a university community; (2) the study involved a reciprocal intervention, the encouragement of caregivers, and motivated users; (3) adequate sleep literacy via e-learning content contributed to motivating the caregivers; and (4) the app could have a better design in comparison with the previously tested ones. To better understand these issues, long-term interventions should be implemented in community-based trials.

Findings from the analysis of the reliability of the data entered by the caregivers were compatible with previous reports documenting the comparison of the sleep time recorded by actigraphy and the time recorded by parents [28-30].

The comparison between the actigraphy and the entered data showed that the latter were sufficiently reliable, particularly with respect to bedtime, which is also consistent with previous findings [28]. Regarding the discrepancies in the sleep duration and number of nighttime awakenings between the actigraphy data and the entered data, previous findings suggest that actigraphy could overestimate the number of awakenings depending on levels of body movement, especially in children whose body movement increases during sleep [30].

These results confirm that the modified actigraphy in this study resulted in findings similar to those of previous studies. Although it was not realistic that all the children wore the actigraphy device during the intervention, it is still a valuable data source for cases in which the caregiver report was judged to be unreliable. On the other hand, caregivers' evaluations of the children's bedtime and wake-up time were reliable in this study, as all the participants were educated and motivated. Taking this into account, the observed improvements in sleep habits, even in this short trial, are likely to reflect reality. The trial use of this app demonstrated the possible effectiveness of reciprocal interaction between caregivers and pediatric sleep experts. Furthermore, it could be effective in alleviating parenting burden among Japanese caregivers. As children's bedtime refusal increases childcare burden for their caregivers, reductions in bedtime refusal are thought to alleviate the psychological and physical burden of caregiving on family life [31].

Although shorter sleep durations in Japanese children are well documented [9], few studies have focused on means to increase caregivers' awareness and change parenting behavior effectively in Japan [32,33]. In addition, the factors that inhibit improvements in sleep literacy and changes in parenting behavior remain unclear. Although evidence demonstrating the importance of children's sleep has accumulated, little attention has been paid to the circumstances and problems faced by caregivers who experience difficulty in improving their children's sleep habits. Mindell et al [34] showed that lifestyle and living circumstances were related to sleep-related conditions in children. Allen et al [35] conceptualized the elements of adequate and good sleep in children in a review of studies examining sleep regularity, bedtime routines, quietness and noise comfort, lights, media use, activities, and family conflict. Fukumizu et al [36] suggested that co-sleeping habits and bedtime irregularity were associated with sleep-related nighttime crying in Japanese children. Changes in childcare practices that improve children's sleep problems sometimes require considerable effort from caregivers, as many factors are associated with healthy sleep in children. For busy caregivers or caregivers who do not receive help with or appropriate advice regarding childcare, it is necessary to not only achieve appropriate levels of sleep literacy but also receive positive feedback regarding their efforts to change their behavior to improve children's sleep habits. In this respect, the interactivity of the app functioned effectively.

From the rate at which caregivers attempted to follow advice (76.8%), we assume that sending advice to caregivers via the app was considered feasible.

The app could have contributed to changes in caregivers' awareness of sleep and their parenting behavior using the PDCA cycle, throughout which they attempted to follow one piece of advice that they themselves chose. These changes in their awareness and parenting behavior could have led to changes in sleep habits and lifestyle (Multimedia Appendix 2). Although this was a short-term trial in which advice was provided only once, bathing time was earlier on weekends with the use of the app. As most of the caregivers who participated in this study worked on weekdays, changing their lifestyles on weekends may have been easier, as they had only one chance to get advice. Further research will include long-term trials that determine the effectiveness of this app in sleep habits on both weekdays and weekends. Future research may also measure caregivers' awareness and behaviors that contribute to infants' healthy sleep before and after the intervention.

Study Strengths

This study shows that the app was successfully designed for reciprocal interaction between caregivers and pediatric sleep experts, which allowed all caregivers to receive personalized and appropriate information and advice. Additionally, the app allowed pediatricians to check caregivers' intervention adherence.

Limitations

This study was subject to some limitations. For example, as participation was voluntary and the participants were recruited from a university community, participants could have been healthier or possessed higher education levels relative to the general population, which could have led to selection bias. In addition, this study was conducted as a single-arm pilot study with a small sample because it aimed to check the usability and acceptability of the app. Furthermore, the intervention was implemented over a short period and it did not focus on the background factors of each family. Further studies should be conducted in consideration of these limitations.

Conclusion

The results of this pilot study showed that the app developed for the intervention was acceptable and usable for Japanese caregivers. In addition, even though this was a preliminary trial, the app showed the scope of changes in children's sleep habits, caregivers' sleep health consciousness, and caregivers' parenting behaviors in Japan. According to the users' feedback, the caregivers welcomed the opportunity to obtain individualized advice that fit the backgrounds and home lives of each family based on the data participants entered via the app. This interactive system is the core feature of Nenne Navi.

Further studies need to be conducted to examine the app's efficacy in improving sleep habits and its effects on follow-up maintenance in order to ensure social implementation of the app. Therefore, we will examine whether users maintain their motivation and high levels of compliance in long-term interventions in subsequent community-based trials. This app is expected to be used in sleep medicine and parental education in Japan and contribute to the expansion of sleep health literacy in families with infants. Moreover, the app could ultimately contribute to improvements in sleep habits and healthy development in Japanese children. Further research with a neuroscientific basis should be done to confirm whether this early sleep intervention leads to desirable brain development.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
List of items for data entry via the app.
[XLSX File (Microsoft Excel File), 24 KB - pediatrics_v3i2e22102_app1.xlsx]

Multimedia Appendix 2
(A) Mean bedtime, (B) mean sleep duration, (C) mean time of finishing infant bathing.
[DOCX File , 79 KB - pediatrics_v3i2e22102_app2.docx]

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Abbreviations

PDCA: plan-do-check-act

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Original Paper

Development of a Web-Based Resource for Parents of Young Children Newly Diagnosed With Autism: Participatory Research Design

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Abstract

Background: The internet provides an ideal avenue to share information, advice, and support regarding autism. However, many websites lack quality control and rarely provide a one-stop resource for families to access necessary, evidence-based information.

Objective: This study aims to use participatory action research (PAR) with end users (ie, parents) and clinicians to develop a web-based resource (Pathways Beyond Diagnosis) to improve timely access to quality, evidence-based information, and support for families after their child is diagnosed with autism.

Methods: The PAR approach involves 4 phases: (1) cooperative researcher-stakeholder planning, (2) cooperative researcher-stakeholder–based action, (3) stakeholder observation, and (4) cooperative researcher-stakeholder reflection. A total of 15 participants (parents, n=3; clinicians, n=9; and researchers, n=3) attended individual or group participatory design workshops. This was followed by the translation of knowledge and ideas generated during the workshops to produce mockups of webpages and content, rapid prototyping, and one-on-one consultations with end users to assess the usability of the website developed.

Results: A total of 3 participatory design workshops were held with the participants, each followed by a knowledge translation session. At the end of the PAR cycle, an alpha prototype of the website was built and a series of one-on-one end user consultation sessions were conducted. The PAR cycle revealed the importance of 6 key topic areas (understanding autism, accessing services, support, gaining funding, putting it all together, and looking into the future) associated with the time of diagnosis, which were incorporated into the beta version of the website.

Conclusions: The development of the Pathways Beyond Diagnosis website using PAR ensures that families have ready access to practical and evidence-based information following a young child's diagnosis. The website guides families to access relevant, reputable, and evidence-based information in addition to summarizing key challenges encountered after diagnosis (ie, grief, sharing the diagnosis) and the importance of self-care.

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KEYWORDS

autism; diagnosis; parents; support; co-design; eHealth

Introduction

In the last 5 years, the proportion of users accessing the internet for health services or health research has increased two-fold from 22% in 2014 to 2015 to 46% in 2016 to 2017 [1]. For parents of children with autism spectrum disorder (ASD), the internet is the most frequently used approach to obtain information [2,3]. Unfortunately, the plethora of web-based information about ASD can be overwhelming and daunting for families [3]. Thus, knowing where to look and what to read is one of the greatest challenges in today's web-based world.

When parents receive their child's diagnosis of ASD, they are often left to navigate the world after the diagnosis on their own without much clarity on next steps. The receipt of a diagnosis often elicits strong emotional reactions from parents and can have detrimental effects on their stress, well-being, and quality of life [4-6]. As a result, it is important to ensure that families know where to turn for more information and support. Although the internet is the preferred medium for sourcing autism information, there are currently no guidelines for finding high-quality websites [7].

With ASD becoming increasingly prevalent, so is the amount of information available. In 1999, Charman [8] reported 104,950 results from a search of the term "autism," and in 2009, the search by Reichow et al [7] (2012) produced 19,900,000 results. After 7 years, (July 4, 2019, 11:38 AM AEST), our search of "autism" returned 176,000,000 results using the Google search engine. This substantial increase in web-based information mirrors the increased awareness and interest in ASD over the last two decades, which also coheres with its increased prevalence [9] over this time. Such an increase makes it even more challenging for individuals, especially parents, to sieve through and determine useful, accurate, and reliable information to guide their journey with their newly diagnosed child. Existing research demonstrates that parents prefer to access information that can be tailored to the child's and family's specific needs [10]. Furthermore, parents rely heavily on local sources of information and value easier access to internet sources that they trust, indicating the need to provide customizable (and locally relevant) web-based information [11,12].

The availability of web-based information and support can enable families with immediate and free access to important and appropriate knowledge and services to assist them. However, web-based information can also confuse families, primarily owing to the sheer volume of information. It is therefore essential that parents are guided toward high-quality and reputable websites. To make this easier for families, our aim was to develop a web-based resource that provides useful postdiagnostic information about ASD and to guide parents to the appropriate web-based websites or services that may benefit them and their child. To develop this resource, we undertook a collaborative approach together with parents and clinicians to identify the necessary support for families soon after their young child's diagnosis of ASD.

Previous studies [13-15] have identified that effective partnerships between researchers, service providers, and key stakeholders, in addition to encouraging individuals' participation in research, can increase the quality of investigations and findings. Furthermore, there is a growing demand for neurotypical researchers to engage with the autistic community to increase the meaningfulness, applicability, and sustainability of research by taking into consideration the ethics, values, and beliefs held by the community [15].

Incorporating knowledge from the autistic community within a participatory action research (PAR) framework can be transformative for participants and researchers. PAR is based on 3 overarching principles: (1) reflection, (2) data collection, and (3) action. A unique method used to develop interventions with the direct input of stakeholders, PAR uses a research strategy aimed at improving health and reducing health inequities by involving people who, in turn, take action to improve their own health [16,17]. PAR seeks to empower individuals who are most affected by the research outcome and involves the collaboration of researchers with the population of interest to solve a problem or develop an intervention [16]. A key element of this process involves collective, self-reflective inquiry for both researchers and participants to understand and improve on practices in which they participate and situations in which they are engaged. PAR is linked to action, which ideally leads to communities having increased control over their lives [17]. This reflects and echoes the overarching principle of inclusion highlighted by the Disability Rights Movement: "nothing about us without us" [18]. Thus, PAR promotes a partnership model that is fundamental to participants holding equal power in research teams and enables local knowledge to be used to achieve relevant, appropriate, and high-quality end goals [17].

Previous studies have effectively used PAR to develop a range of web-based resources, including electronic learning and health promotion materials, an asthma self-management app, an electronic Individual Care Plan for children with disabilities, and a mental health e-Clinic [19-22]. All studies shared similar features where reflection, data collection, and action were used to co-design and build these resources with important insights and expectations brought to the forefront by end-user involvement. This research reinforces the benefits of end-user involvement in the development of web-based resources.

The rationale behind the use of PAR in the development of web-based resources about autism may indicate that active engagement of end users can reduce the 17-year gap that is common in translational research [23]. This paper reports the developmental process of a web-based resource for parents of newly diagnosed children with ASD. The aim of this study was to use PAR with end users (ie, parents of children with autism) and clinicians together with our research team to co-design and build a website to improve timely access and provide better guidance to evidence-based high-quality autism information and resources following a diagnosis of ASD within the Australian context.

PAR

Participatory design methodologies, which were developed in the late 1960s and early 1970s, emphasize the importance of involving all stakeholders (including end users, developers, and researchers) in the design and development of resources to ensure that the end product meets everyone's needs. It also improves usability and increases the engagement of users [19,21,24] with the end product. In collaboration with study participants and a professional advisory group, PAR was identified as the most appropriate participatory design methodology for the development of a website for families of newly diagnosed children with ASD.

The development process was based on the following steps: planning, action, observation, reflection, and using the new learning to inform further action planning [25,26]. Although PAR shares similarities with traditional research (ie, design, implementation, and evaluations), it differs in that the stakeholders are integral to all parts of the research process. Participants' active role in the outcome sets PAR apart from traditional research methods where the participants tend to be more passive in their receipt of research outcomes [17]. A key component of PAR is flexibility; the observation and reflection steps promote cumulative learning, which enables modification to the outcome and encourages participant empowerment. Furthermore, PAR also enables participants to be realistic and specific about the practicality of the proposed intervention model.

Objective

Our overall objective was to develop a web-based information model that empowers parents by providing them with timely access to high-quality evidence-based information and support following the diagnosis of their child with ASD. Using an informational model to improve parental and family outcomes, parents can be better prepared and more confident as they tackle their new journey in raising their child with autism. Furthermore, providing families with one key website that redirects them to other relevant high-quality resources can help them easily navigate the plethora of autism-specific information available on the (often confusing) World Wide Web.

We used the theoretical foundation of self-efficacy, which has been demonstrated to predict and promote behavior change and improve health outcomes in a range of conditions (eg, diabetes mellitus) [27]. Self-efficacy refers to an individual's belief in their capabilities to organize and execute a course of action to produce given attainments [28]. Furthermore, the use of behavior change theory itself in intervention development has been associated with greater intervention effectiveness [27]. This, in combination with evidence-based content and strategies as well as key stakeholder input, serves to optimize individual and family outcomes.

In this study, data obtained from PAR informed the development of the abovementioned website for parents of young children newly diagnosed with ASD. Specifically, PAR was used to gather information about what parents need to know after receiving a child's diagnosis and how to best provide this information within a web-based format to enhance accessibility and usability. The aim was to establish a *self-contained* website that does not require regular input by a health care provider or other third party. This information model can provide an efficient and economic avenue for health and government bodies and allow families to gain timely and ready access to relevant information to support their child and family's well-being in the critical time after diagnosis.

Methods

Participants

The target population was recruited via convenience sampling through email invitation to autism industry partners and parents from a previous qualitative study [10]. As outlined in the PAR methodology, collaborative partnerships were formed between key stakeholders (ie, participants), including parents of children with autism, health professionals, and researchers. A total of 13 parents, who previously received their child's early diagnosis of ASD (<36 months), were invited to provide knowledge and feedback regarding postdiagnostic support. Two mothers and one father (3/17, 23%) agreed to participate. Their demographic details are presented in Table 1. A total of 17 senior health professionals in the autism field were invited to participate in an advisory group for the development of this resource (Table 2). From these health professionals, 53% (9/17) agreed to participate, comprising 3 pediatricians, 3 psychologists, 1 psychiatrist, 1 social worker, and 1 occupational therapist.

In partnership with autism researchers (n=3), the health professionals (n=9) and parents (n=3) comprised the overall participant sample of 15 individuals. As participants progressed through each PAR phase, some participant attrition was observed: Phase 1: n=15; Phase 2: n=10; Phase 3: n=9; and Phase 4: n=8, with an attrition rate of 46% from Phase 1 to 4. None of the participants received compensation for their contribution to this research.

Table 1. Parent participant profile.

Characteristics	Parent 1	Parent 2	Parent 3
Parenting role	Father	Mother	Mother
Age (years)	46	42	54
Marital status	Married	Married	Separated
Place of birth	Australia	Australia	Lebanon
Time elapsed since child's diagnosis (years)	1.5	1	7
Child's diagnosis	ASD[a], LD[b]	ASD	AD[c], ID[d]
Child's age at diagnosis (months)	17	31	22
Gender of the child	Male	Female	Male
Household income, Aus $ (US $)	>175,000 (127,015)	95,000-115,000 (68,951-83,467)	35,001-55,000 (25,404-39,919)

[a] ASD: autism spectrum disorder.

[b] LD: language delay.

[c] AD: autism disorder.

[d] ID: intellectual disability.

Table 2. Professional participant profile.

Professions	Sex	Years of experience in autism	Specific area of expertise
Pediatrician	Male	15	Early diagnosis, comorbidities, teaching
Pediatrician	Female	28	Prevalence, cause, diagnosis, prognosis, intervention, research
Pediatrician	Female	38	Diagnosis, intervention, research
Psychologist	Male	22	Research
Psychologist	Male	12	Diagnosis, intervention
Psychologist	Female	10	Diagnosis, intervention
Psychiatrist	Female	20	Diagnosis, intervention, research
Social worker	Female	15	Child development, intervention, family well-being
Occupational therapist	Female	20	Intervention, diagnosis
Researcher	Female	35	Research in early diagnosis, early intervention, social cognition, parental experience, employment
Researcher	Female	14	Research in early identification and diagnosis
Researcher	Female	11	Diagnosis, intervention, family well-being, mental health, parenting, research

Phase 1

The initial participatory design workshop (n=15) was held with parents of children with autism (n=3), health professionals who work with families affected by autism (n=9), and researchers in the field of autism (n=3). The majority of these participants were female (11/15, 73%).

Phase 2

A total of 10 participants engaged in Phase 2, which consisted of parents (n=3), health professionals (n=4; 2 psychologists, 1 occupational therapist, and 1 pediatrician), and researchers (n=3), with the majority being female (80%).

Phase 3

A total of 9 participants remained involved in Phase 3, the observation phase, where a tentative website structure was developed (ie, alpha prototype). A group meeting of health professionals and researchers was then held (3 researchers, 2 psychologists, and 1 occupational therapist).

Phase 4

A total of 8 individuals participated in Phase 4 (one-on-one end user consultation sessions), who were predominantly female (7/8, 88%), comprising 2 mothers, 1 father, 1 psychologist, 1 occupational therapist, and 3 researchers.

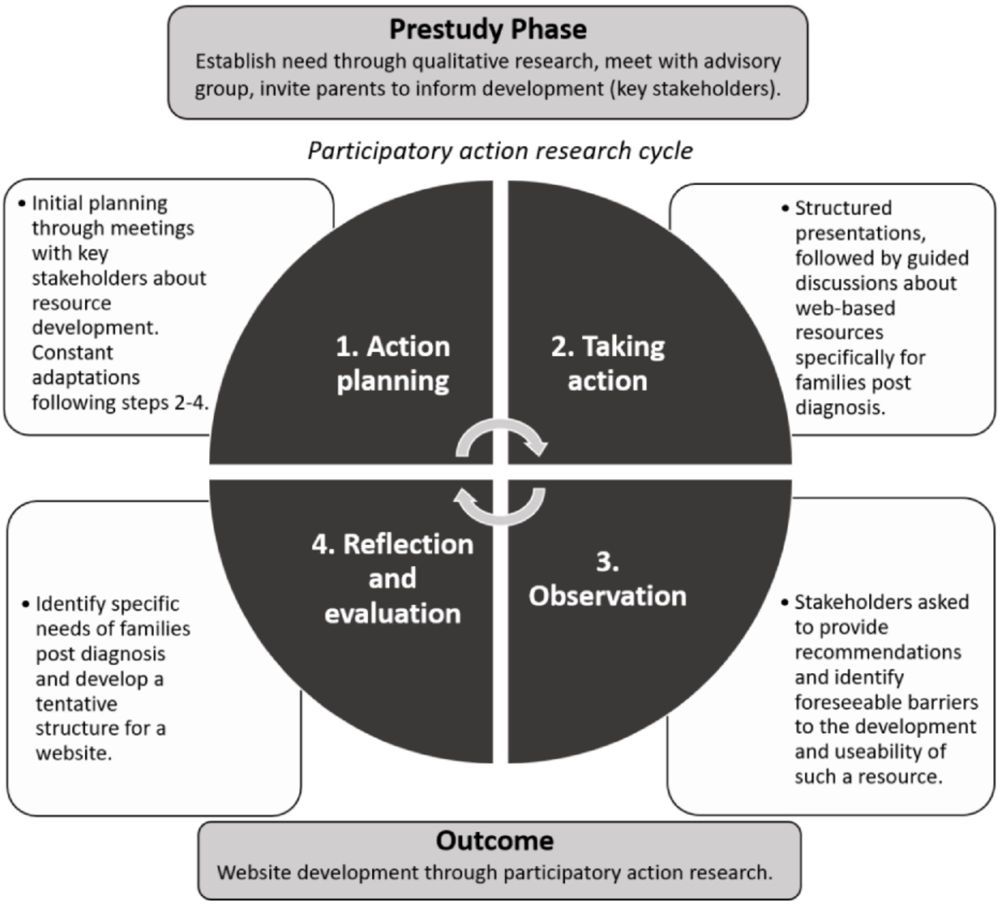
Procedure

Ethics approval was obtained from the University Human Ethics Committee. The meetings or workshops were conducted either face-to-face or virtually at La Trobe University in Melbourne, Australia in a secure, private room to ensure confidentiality. Participants who engaged virtually were advised to remain in a quiet and confidential space for the duration of the meeting. Given the plethora of autism information available on the web, it was important that this resource be optimized within the current web-based arena to ensure easy accessibility by parents, given all other available websites. On the basis of the literature on search engine optimization, there are several key features distinguishing good versus poor website optimization: (1) use of key phrases, (2) consistent web theme, (3) organized content, (4) optimized links, (5) professional communicators (ie, practitioners or researchers), and (6) web-based promotion through various reputable sources [29,30]. A qualitative research design using the PAR cycle guided the development of an informational model for parents after diagnosis. Features of website optimization were encountered, reflected upon, and discussed throughout the phases of development.

The PAR cycle involves 4 major phases: (1) action planning, (2) taking action, (3) observation, and (4) reflection and evaluation. These phases are depicted within the PAR model in Figure 1 and have been adapted from previous research by Munns and colleagues [31]. In this study, Phases 1 to 3 included participatory design workshops, where participants attended individual and/or group meetings. This was followed by knowledge translation sessions where cooperative researcher-stakeholder ideas generated during workshops were used to produce mockups of webpages and content. Finally, in Phase 4, rapid prototyping of the end product occurred and one-on-one consultations with end users assessed and informed the usability of the website.

A total of 4 participatory design workshops, 4 knowledge translation sessions and 3 one-on-one end user consultations were conducted over a period of 6 months. Throughout Phases 1 to 3, health professionals predominantly chose to participate in group meetings, whereas parents preferred individual meetings with the lead author or researcher.

Figure 1. Model of participatory action research.



Action Planning (Phase 1)

A total of 4 participatory design workshops (1 group meeting for health professionals and 3 individual meetings for parents) were conducted as part of the *Action Planning* stage, each lasting 30 to 60 min. During Phase 1, researchers presented examples of current web-based information about autism, how it was being utilized by families, and where the gaps were regarding postdiagnostic support. Through consultation and cooperative researcher-stakeholder planning, ideas were generated for the development of a postdiagnostic resource for families of newly diagnosed children.

Taking Action (Phase 2)

The knowledge and ideas generated in Phase 1 were translated into mockups of webpages. A total of 4 knowledge translation sessions (1 group meeting and 3 individual meetings) were conducted where structured presentations were given to stakeholders (health professionals and parents). Following the structured presentations, participants engaged in a guided discussion about what type of web-based resource would be beneficial and how it could be utilized to meet a family's needs after diagnosis. Following these guided discussions, participants were asked to respond to 2 open-ended questions or requests: "Please list any recommendations you have for the development and dissemination of this online resource for parents" and "Please list any barriers you foresee in the development and use of such a resource."

Observation (Phase 3)

Qualitative results were compiled for the observation phase (Phase 3) and presented to all participants, including parents, health professionals, and researchers. A final meeting was held with the health professionals and researchers where the key stakeholders collaborated to develop a tentative structure for a website utilizing evidence-based information. In addition, the 3 parents also participated in individual meetings, with the lead author providing recommendations and identifying foreseeable barriers to the development and usability of this resource. On the basis of these results and through collaboration with the researchers, a plan was formulated by all participants to guide the alpha build of the website. On observation, participants emphasized the need for adaptations to this, with specific content added to accommodate parents of newly diagnosed children (ie, various topics added: grief or loss, family support, and funding information).

Reflection and Evaluation (Phase 4)

Participants were provided with a hard and/or electronic copy of the beta version of the website for reflection and evaluation. Stakeholders were asked to reflect and evaluate the layout, contents, and utilization of the resource. One-on-one consultations were conducted with the 3 parents who also provided general written feedback detailing the pros and cons of the resource, together with suggestions for improvement. This participatory data collection strategy is described as beneficiary assessment (BA) and involves asking participants, specifically those who will be the intended beneficiaries, about their use of a resource, satisfaction with that resource, and ideas for changes that might be needed [32]. The BA process enables researchers to gain insights from the beneficiaries to improve the quality of development of an intervention or resource.

Data Analysis

To address the specific research objective, an inductive approach to content analysis was adopted as an efficient process to categorize raw data and generate an information model. A moderator guide, including a series of questions, was used and revised during the research process [33] to guide discussion through each phase and development of the resource. Data from the participatory design workshops, knowledge translation sessions, and one-on-one consultations were collected. Examples of questions in the moderator guide are presented in Textbox 1. Prompts related to participant responses were used to guide the ensuing discussion.

Textbox 1. Examples of questions in the moderator guide.

- What gaps do you see in post-diagnostic support for families of children diagnosed with autism?
- What questions do you receive from parents immediately after diagnosing their child?
- In retrospect, what would have been most valuable to you after receiving your child's diagnosis?
- What barriers do you foresee in the development and use of a post-diagnostic resource?
- What do you consider essential information for families post diagnosis?
- How do you see this resource standing apart from what already exists on the web?

Thematic analysis [34] was used to interpret the qualitative data according to the following key themes: (1) website content, (2) user interface, (3) referral to existing resources, and (4) interaction of the website with stakeholders or end users. Data were thematically analyzed through categorization, clustering, and identification of the common subthemes that emerged through phases 1 to 4 [34-36]. Records of all information including meeting discussions, written feedback, and comments obtained in phases 1 to 4 were then grouped and interpreted by the lead author. Individual themes and related content were discussed by the researchers, rationale was given for grouping and interpretation of data, and differences in opinion were discussed until consensus was reached. A codebook was developed following data collection to guide the thematic analysis. The codebook was referenced throughout the data analysis to maintain consistency. Mechanisms such as peer debriefings and member checks were used for credibility, along with an acknowledgment of known research limitations to ensure trustworthiness of the data [37]. Information to be contained within this resource was evaluated based on 5 guiding principles (Textbox 2), which were used to determine the inclusion or exclusion of any links and key information within the proposed website model.

Textbox 2. Guidelines used to determine website inclusion.

Standards for website inclusion:

- Peer-reviewed research literature (evidence based)
- Information developed by a tertiary institution
- Information developed by an academic or clinical expert in the autism field
- Details from a government organization
- Details from a leading not-for-profit autism organization

Results

Iterative participatory design workshops, which formed the basis of the PAR cycle, were utilized for the co-design and building of this resource. The workshops revealed the importance of 8 key components that would be fundamental to the development of a user-friendly website:

1. A clear and succinct homepage.

2. An easy-to-read description of autism.

3. Information about how to access services to help the child.

4. Various supports that are available and links to existing websites or resources.

5. A summary of funding avenues.

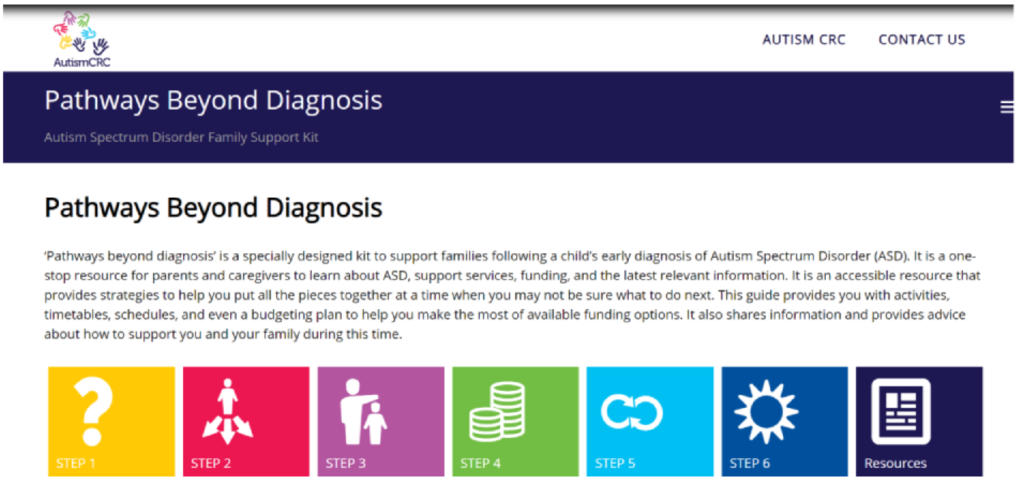
6. A snapshot of practical strategies to help with child behavior.

7. A summary of how to make sense of the information—“putting it all together.”

8. A brief summary of information about the future.

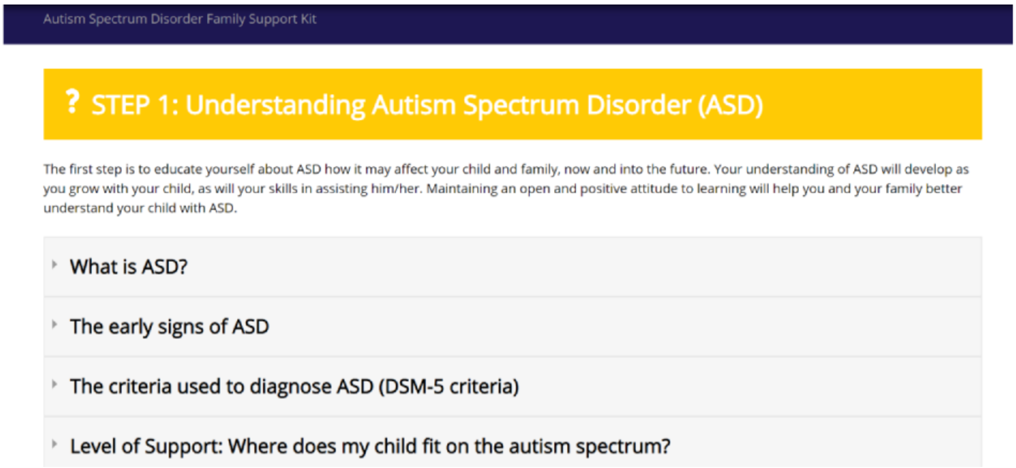
These specific components (Figures 2-8) informed the development and the alpha build of the *Pathways Beyond Diagnosis* website. Each of these 8 components can be accessed directly, providing the parent or primary caregiver with the option to access the information most relevant to them and their family at the time. The entire site can also be accessed sequentially, if preferred.

Figure 2. Component 1: Website Home Page.



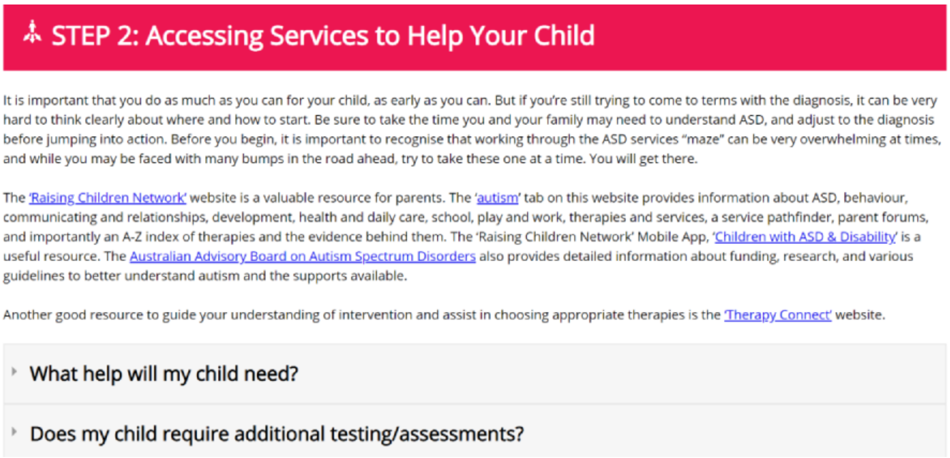
‘Pathways beyond diagnosis’ is a specially designed kit to support families following a child’s early diagnosis of Autism Spectrum Disorder (ASD). It is a one-stop resource for parents and caregivers to learn about ASD, support services, funding, and the latest relevant information. It is an accessible resource that provides strategies to help you put all the pieces together at a time when you may not be sure what to do next. This guide provides you with activities, timetables, schedules, and even a budgeting plan to help you make the most of available funding options. It also shares information and provides advice about how to support you and your family during this time.

Figure 3. Component 2: Understanding Autism page.



The first step is to educate yourself about ASD how it may affect your child and family, now and into the future. Your understanding of ASD will develop as you grow with your child, as will your skills in assisting him/her. Maintaining an open and positive attitude to learning will help you and your family better understand your child with ASD.

Figure 4. Component 3: Accessing Services to Help Your Child page.



STEP 2: Accessing Services to Help Your Child

It is important that you do as much as you can for your child, as early as you can. But if you're still trying to come to terms with the diagnosis, it can be very hard to think clearly about where and how to start. Be sure to take the time you and your family may need to understand ASD, and adjust to the diagnosis before jumping into action. Before you begin, it is important to recognise that working through the ASD services "maze" can be very overwhelming at times, and while you may be faced with many bumps in the road ahead, try to take these one at a time. You will get there.

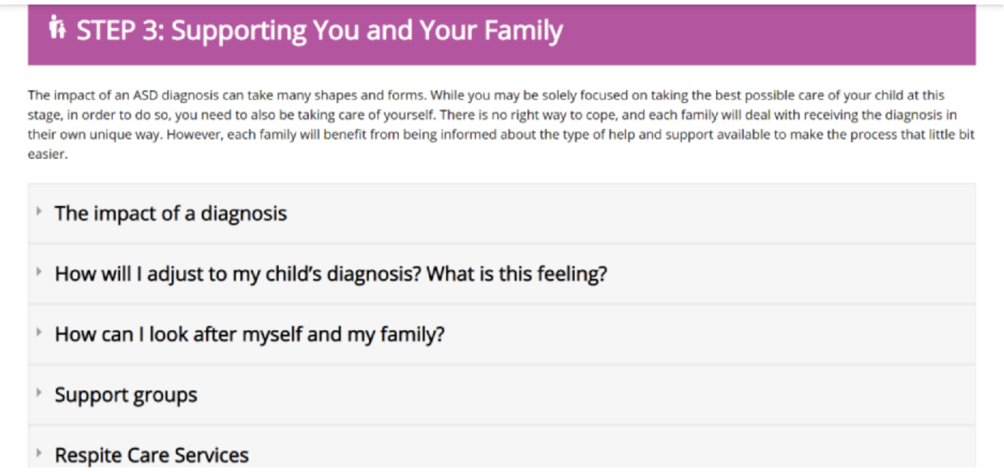
The 'Raising Children Network' website is a valuable resource for parents. The 'autism' tab on this website provides information about ASD, behaviour, communicating and relationships, development, health and daily care, school, play and work, therapies and services, a service pathfinder, parent forums, and importantly an A-Z index of therapies and the evidence behind them. The 'Raising Children Network' Mobile App, 'Children with ASD & Disability' is a useful resource. The Australian Advisory Board on Autism Spectrum Disorders also provides detailed information about funding, research, and various guidelines to better understand autism and the supports available.

Another good resource to guide your understanding of intervention and assist in choosing appropriate therapies is the 'Therapy Connect' website.

What help will my child need?

Does my child require additional testing/assessments?

Figure 5. Component 4: Supporting You and Your Family page.



STEP 3: Supporting You and Your Family

The impact of an ASD diagnosis can take many shapes and forms. While you may be solely focused on taking the best possible care of your child at this stage, in order to do so, you need to also be taking care of yourself. There is no right way to cope, and each family will deal with receiving the diagnosis in their own unique way. However, each family will benefit from being informed about the type of help and support available to make the process that little bit easier.

The impact of a diagnosis

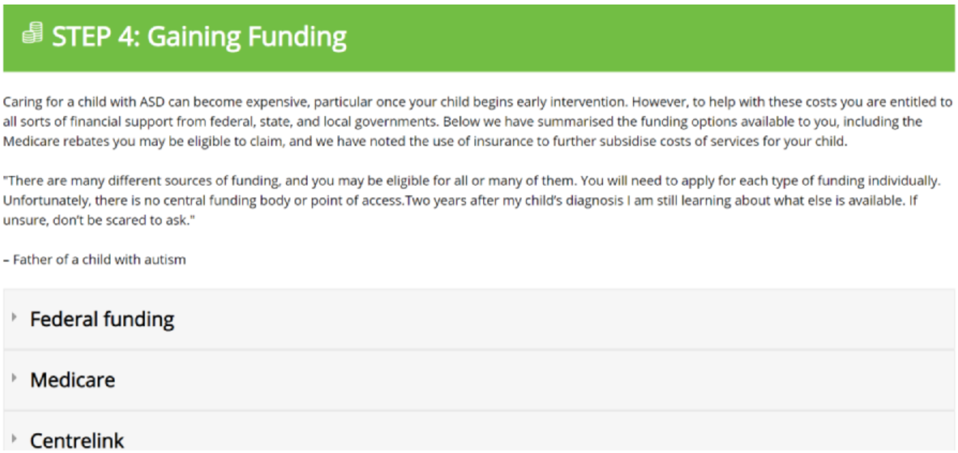
How will I adjust to my child's diagnosis? What is this feeling?

How can I look after myself and my family?

Support groups

Respite Care Services

Figure 6. Component 5: Gaining Funding page.



STEP 4: Gaining Funding

Caring for a child with ASD can become expensive, particular once your child begins early intervention. However, to help with these costs you are entitled to all sorts of financial support from federal, state, and local governments. Below we have summarised the funding options available to you, including the Medicare rebates you may be eligible to claim, and we have noted the use of insurance to further subsidise costs of services for your child.

"There are many different sources of funding, and you may be eligible for all or many of them. You will need to apply for each type of funding individually. Unfortunately, there is no central funding body or point of access.Two years after my child's diagnosis I am still learning about what else is available. If unsure, don't be scared to ask."

– Father of a child with autism

Federal funding

Medicare

Centrelink

Figure 7. Component 6: Putting it all Together page.

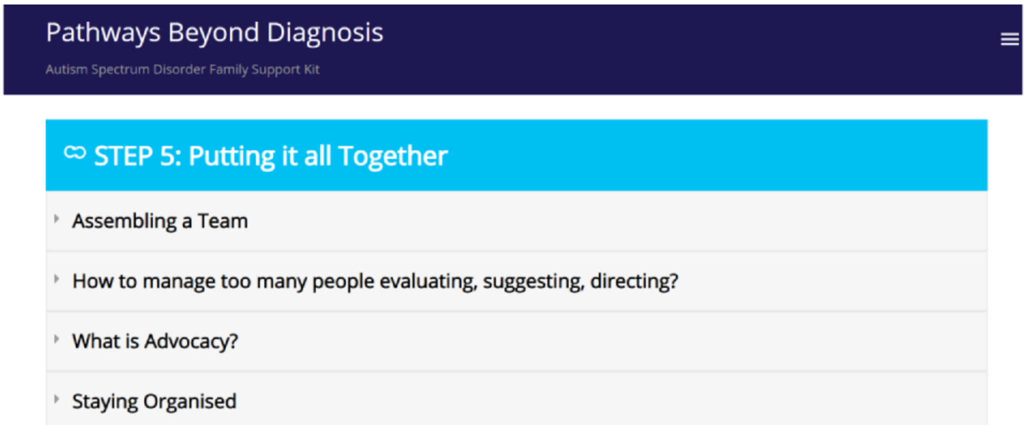


Figure 8. Component 7: Looking into the Future page.

Component 1: Website Home Page

In relation to the user interface of the homepage, parents and health professionals agreed that it should be easy to navigate without using “too much text.” Thus, short and concise subheadings were used to direct individuals to the relevant content area. As most participants preferred icons instead of text, they were adopted as illustrated in Figure 2. Participants suggested the removal of a “contents style” page and lengthy instructions, opting instead to provide parents the opportunity to self-explore the website and navigate to the subtopics of their choice. Participants also proposed that “diagrams and tables” be used to describe ideas and summarize information instead of blocks of text to ease comprehension and reduce the common experience of parents “feeling overwhelmed” with information after diagnosis.

Component 2: Understanding Autism

Participants suggested the use of realistic and practical examples when describing characteristics of autism, allowing those who access the resource to easily make sense of the definitions. In addition, participants noted that some of the language describing autism was not user friendly, describing it as “autism-expert speak.” Descriptions were therefore simplified using lay language to ensure clarity and comprehension, as participants emphasized that the reader, who is new to the autism world, “may not yet understand this” terminology, causing additional stress in trying to make sense of it.

Component 3: Accessing Services to Help Your Child

All participants reported that there is "so much information available online," the website should be focused on redirecting parents to the "best information" that already exists. In addition, they recommended ensuring that parents of young children are educated on “selecting an intervention that is right for them.” Participants also stressed the importance of defining terminology and the careful use of language. Parents stated that “the term early intervention means absolutely nothing to someone outside the field, until they are familiar” and suggested that specific examples be given. They also suggested that the website note that “parents do not need to do all the interventions available to them,” but instead they “can try various approaches to see what their child responds to and suits the family best.”

Component 4: Finding Support

Finding support was centered on parental self-care, adjustment to diagnosis, access to support groups, where to get help, and how a parent can help their child in their everyday interactions. Initially, the section on *finding support* focused heavily on parent support and self-care. However, parents expressed that although it was important to include information about parental self-care, following a diagnosis, a parent’s first focus is “What will help my child? How can I find support for them?” rather than on how to help themselves. Taking participant feedback into account, the section on *finding support* was restructured to include information for parents on how to support themselves, their family, *and* their child.

Component 5: Gaining Funding

Given the different sources of funding provided by various bodies, participants noted that families need to be made aware of these sources and their eligibility for them. It was also emphasized that the application process may be challenging as parents may have to apply for each type of funding individually; thus, the information provided within the website should highlight the specific funding and support available, with help regarding how parents access it.

Component 6: Putting It All Together

Participants emphasized the need for a component that brings all relevant information together. To move onto the next steps, families need to have the knowledge of how to assemble a team, stay organized, and advocate for their child. Although having a primary service provider or *key worker* as a central point of contact may be ideal, participants commented that this is unrealistic as it is often difficult to find the right person and one who also has the capacity to do this. Participants noted that it is much more likely that the “parents will be fulfilling this role.” Furthermore, they stated that it is important to communicate this reality to parents of newly diagnosed children to prepare them for various tasks, such as organizing appointments with therapists and managing intervention schedules. To assist with this, participants suggested an *example schedule* be included within the website that families can utilize as a template, as this visual representation is helpful to “maintain focus.”

Advocacy was also highlighted by participants as an important element of the postdiagnostic journey. Parents are in the best position to advocate for their child, but many never have had to take on this role in the past. As a parent of a newly diagnosed child, they are faced with the new reality of becoming an *autism advocate* overnight. Therefore, participants felt it was essential that the website provide families with guidance on how to become a successful and effective advocate.

Component 7: Looking into the Future

Finally, in relation to future-oriented activities (such as preschool, playgroups, and other recreational activities), participants suggested that autism-specific examples and resources be provided to families “because often parents aren’t aware these services even exist.” Participants also emphasized that parents should be made aware of “inclusion support,” support that may help their child and family transition into intervention and other early childhood environments and further help them feel a sense of belonging in the chosen setting. Participants also expressed the importance of sharing the reality that there is inconsistency regarding support services, such that parental expectations can be managed, and emphasizing the need for their advocacy skills that will benefit them. For example, some families may receive inclusion support in some services (ie, preschool) but not in others (ie, child care). Participants were also warned from focusing too far into the future as this may hinder the parent’s ability to focus on the present.

Discussion

Principal Findings

As stated previously, the aim of PAR is to develop interventions that take into account the ideas and perceptions of those directly affected by the circumstances [38]. Importantly, the PAR process emphasizes the involvement of all stakeholders (ie, parents, health professionals, researchers) and acknowledges the key roles they play in the development of the end product to help ensure that it meets everyone’s needs, improves usability, and increases engagement of end users. This study specifically aimed to develop an information model that described the critical domains or topic areas that parents would benefit from following a child’s diagnosis of ASD. Together, the key stakeholders (ie, parents, health professionals, researchers) identified the critical domains that should be addressed in this information model. Following participant feedback, a web-based resource was suggested as the preferred delivery mode of postdiagnostic information.

The *Pathways Beyond Diagnosis* website aims to provide a one-stop resource for families of newly diagnosed young children, including a summary of important postdiagnostic information: autism education, services and support, funding, and practical strategies. It will also redirect families to other useful and reputable websites already available on the web. On the basis of the existing literature and participant feedback, 6 components were identified as the most pertinent for families after diagnosis. Although the key factors are documented in the literature and available on various websites [39-41], there is no single website that addresses them in one place. Having access to a web-based resource, such as *Pathways Beyond Diagnosis*, provides families and clinicians with a unique navigation or information model that addresses many of the initial questions raised after a child’s diagnosis of autism, either via the website itself or by redirecting individuals to other relevant sources.

As the internet continues to be the most frequently used method of accessing information and support by families of children with ASD, there is an increasing need for high-quality evidence-based websites [2,7]. By engaging with end users to drive the development of *Pathways Beyond Diagnosis*, we are addressing the needs of families and clinicians and engaging with the autistic community to increase the meaningfulness and applicability of the end product [15].

Strengths

A key strength of developing the *Pathways Beyond Diagnosis* website is that information was gained from key stakeholders for a range of perspectives. Importantly, the parent perspective was combined with that of relevant clinicians to inform development. Furthermore, this resource will be freely available on the web as well as be accessible as a printable PDF document. This means that it does not discriminate based on families’ socioeconomic status or geographical location. Furthermore, it was intended as a one-stop resource such that families can promptly be redirected to appropriate websites rather than reinventing the wheel and repeating information that already exists elsewhere.

There is great value in the use of PAR methodology as it allows participants to provide in-depth descriptions of the issues raised by parents and health professionals when accessing web-based information about autism. In addition, participants also had the opportunity to provide realistic advice around the development of practical web-based resources to support parents. Furthermore, the funding and service pages are tailored to the geographical location but can easily be adapted to suit other areas, contexts, and cultures.

Limitations

Engaging a larger sample of parents whose child had previously been diagnosed with autism proved to be a significant challenge. As a result, the data collected were explored qualitatively and each participant's feedback was examined individually. It is important to note this as a limitation as additional data may have further informed program development and improvement. However, there is value in the lived experience that was communicated in the 3-parent descriptive responses. The lived experience gives credence to the useful and practical elements of the parent data. One parent revealed that their child was diagnosed 7 years before the study and, although the child was diagnosed early (<36 months), the time elapsed as diagnosis was significantly longer than the other 2 parents (12-18 months). Hence, this is a limitation whereby the information and knowledge shared by this parent about postdiagnostic support may differ from the other parents with more recent child diagnoses. However, on examination of this parent's data, this was not the case.

A further limitation includes the language barrier, as the website has not been translated into other languages, limiting the population it can benefit to those who only understand English. In future versions, consideration should be given to culturally and linguistically diverse populations to allow for greater equity in accessing such web-based resources. For example, provision for a translating option on the homepage. An evaluation of the website by parents who have used it following the diagnosis of their child will be an important next step to determine its usefulness, accessibility, and impact on parental well-being.

Although the web-based information platform may prove to be beneficial for many, it is important to note that the absence of a built-in blog or forum for parents to interact was identified as a limitation by participants. This is an important element to consider for future versions, particularly given the strength identified in social support as a moderator of stress in parents of children with autism and the benefits of *networked empowerment*, the term used to describe how parents find other parents and facilitate each other's access to resources and support [42,43]. When parents connect with other parents experiencing similar challenges, they discover new ways to promote advocacy, access support, and maintain their well-being. Furthermore, limited access to developers and researchers meant that data could only be analyzed by 1 researcher and then reviewed by a team of researchers. Although this approach allowed research insights to inform design and development, additional analysts would provide greater reliability in the findings. Future iterations of the website should aim to address some of these limitations by including a built-in blog that gives families the opportunity to share experiences, learn from each other, and access peer support. Including a team of developers and researchers from the outset to focus exclusively on data analytics may also strengthen future website development. Despite these limitations, given that this website development is pioneering work, it is important that the academic community understands the process behind its creation.

A good website should be an ever-changing platform. Websites offer the flexibility to update information to accommodate simultaneous changes in knowledge and services as they occur in the real world. With this in mind, limitations of this research should be viewed instead as new learning that will help enhance future iterations of the *Pathways to Diagnosis* website.

Conclusions

Our web-based information model is based robustly on a theoretical foundation of self-efficacy, which has been demonstrated to predict and promote behavior change and improve health outcomes in a range of conditions [27]. In addition, evidence-based content and strategies, together with stakeholder input and usability testing through PAR methodology, resulted in an optimally designed website to improve access to relevant information for parents of newly diagnosed children with ASD and complement health care delivery, particularly during the stressful time after diagnosis.

Consumers' increasing use of the internet for health information and ongoing revolutions in social media are strong indicators that consumers are primed to welcome a new era of technology where new knowledge is available at their fingertips in the comfort of their own home. However, the full potential of web-based interventions and information models is hindered by limited knowledge regarding their efficacy and effectiveness, high prevalence of usability errors, and high attrition rates [27]. We intend to address these limitations by assessing the efficacy and effectiveness of the *Pathways Beyond Diagnosis* website, identifying characteristics associated with website use and attrition, including whether it is helpful and easy to navigate, website optimization, and understanding the benefits or disadvantages associated with such a resource. A summative evaluation of the website will examine implementation through a usability study and evaluation surveys to determine the impact on family quality of life and parents' self-efficacy, empowerment, and improved knowledge following wide access to this resource. With appropriate information and resources, parents can work toward understanding the diagnosis, coping with their own emotions, and adapting positively to maximize personal psychological and family outcomes.

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Authors' Contributions

Aspasia Stacey Rabba: Conceptualization, Methodology, Formal Analysis, Writing - Original Draft.
Cheryl Dissanayake: Conceptualization, Methodology, Writing - Review and Editing, Supervision.
Josephine Barbaro: Conceptualization, Methodology, Writing - Review and Editing, Supervision.

Conflicts of Interest

None declared.

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Abbreviations

ASD: autism spectrum disorder
BA: beneficiary assessment
PAR: participatory action research

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Original Paper

Availability and Quality of Web Resources for Parents of Children With Disability: Content Analysis and Usability Study

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Abstract

Background: The internet is a valuable resource for parents of typical children, who are looking for information about their children's growth and development and how to boost them. However, for parents of children with special needs, especially for non–English-speaking parents, there are anecdotal reports stating that specific and accurate information is not available on the internet.

Objective: This study aims to describe the type of information available on the internet for French-speaking parents of children with disability as well as assess the quality of the information collected.

Methods: We carried out a search of the existing relevant websites targeted at parents of children with disability. We used a validated instrument to extract structural, textual, and visual characteristics of these websites and evaluate their usability.

Results: In all, 42 websites were analyzed; of these, the information had been validated by a trustworthy source in only 18 (43%) websites. Networking opportunities for parents were available in only 7 (17%) websites. Most websites provided information related to autism spectrum disorder (20/42, 42%) and learning disabilities (19/42, 45%), and only a few websites discussed other disability types such as behavorial disorders and developmental language disorders (4/42, 10% each). Community, social, and civic life (9/42, 22%); domestic life (12/42, 29%); and mobility (15/42, 36%) were the less frequently covered topics. With regard to the usability evaluation, 22 of the 42 (52%) websites received a global score <70%, whereas 20 (48%) scored ≥70%

Conclusions: Although the internet is an infinite source of information, it is not necessarily actionable for parents of children with disability. Some information remains difficult to find online, and networking opportunities with other parents dealing with similar challenges are scarce.

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KEYWORDS

disabled child; parents; health knowledge; internet-based intervention; validation study

Introduction

Parents of children with disability, such as those with impairments, activity limitations, and participation restrictions [1] (eg, autism spectrum disorder [ASD], cerebral palsy, and Down syndrome), have a greater need for support because of the additional responsibilities related to their child's care [2] than do parents of children with typical development [3-5]. The child's condition may considerably affect the parents' routines, priorities, and social network [6]. This may lead to increased stress levels [7] and emotional distress, partly due to insufficient social support [6,8]. Given these constraints, parents of children with disability tend to have greater needs for information and networking [9-11].

When parents receive the initial diagnosis of their child's disability, they may have difficulty assimilating all the information provided by professionals, especially because of the emotional upheaval they experience [12]. Moreover, they may encounter new challenges (eg, how to bathe a growing child with paraplegia, or how to educate a teenager with cognitive impairment about certain sexually inappropriate behaviors in public) any time, but professionals may not be available at all times to advise them. This is one of the primary reasons why these parents turn to the internet for information [9,10,13,14]. However, considering the individualized profile of each family of children with disability, the information available online does not necessarily meet all their specific needs [15,16].

Such parents also often seek emotional support from other parents who have had a similar experience [9,17]; they believe maintaining a good, supportive social network helps them find tangible solutions to emerging issues as well as receive significant emotional reassurance [18,19]. This sharing of information is important to help them relieve the stress and alleviate the feeling of burden that may be associated with their challenges [15,19-21]. Parents find such networking and interaction as important as finding relevant information on the internet [22]. Although the internet could conceivably offer an opportunity for resourceful networking, to our knowledge, no study has examined this dimension of the use of internet. Moreover, given that most of the information available on the internet is in English, parents who do not read English may not always be able to readily access relevant information.

Finally, little is known about the format and characteristics of existing internet pages that parents of children with disability access. Only 62% of parents pay attention to whether the health care information available on websites is reliable [23], and only half of them consider themselves to be able to accurately assess the quality of the information found online [24]. These findings suggest that parents could blindly use any information found on the internet and might, in the worst case, endanger their child or themselves. Given that safety of the child is important and considerable amounts of knowledge is readily available about the descriptive characteristics that enhance usability of websites [25], it thus appears timely to provide an in-depth portrait of such internet resources.

Therefore, in this study, we aimed to (1) identify existing websites aimed at providing information to parents of children with disability, (2) summarize the content of such websites, and (3) evaluate the quality of information they provide.

Methods

This study was conducted in a French-speaking region of Canada, within an integrated knowledge translation framework [26-28]. The study included an advisory committee comprising 2 parents (the knowledge holders) and 2 researchers (the emissaries who have the authority to disseminate this knowledge). The researchers delineated the research question and subsequently discussed the methodology as well as the interpretation of the results to ensure that the project fulfilled the parents' initial needs (ie, to evaluate the quality of websites they use to access information). The question was brought forward by the parents on the advisory committee (ie, parents of children with disability) who believed that the content on the internet could be improved to address their information needs more adequately.

Accordingly, in the first step of this study, these parents suggested 10 websites in French that they accessed frequently. The following selection criteria were used to select the websites: (i) publicly available, (ii) written in French or in English, and (iii) intended for parents of children with disability, aged between 3 and 12 years (with the exception of one site, "Portail Enfance," aimed at health professionals and students, but its content was, in our opinion, relevant and usable by parents). Websites presenting information about disabilities with a high prevalence (ie, ASD, cerebral palsy, intellectual disability, and learning disabilities) were first explored [29]. In the second round, websites were identified using common vocabulary search terms (eg, French counterparts of "autism spectrum disorder tips and tools," and "special needs in cerebral palsy") on Google. Finally, we also included websites that were found in the resources linked to the previously selected websites that were considered relevant and coherent with our selection criteria. We stopped searching for new websites when the structural, textual, and visual characteristics of the most recent websites identified were similar to at least one of the other already analyzed websites. In all, 42 websites were selected for the analyses.

The data extraction process aimed to collect descriptive characteristics of the websites (Table S1 in Multimedia Appendix 1). Two research assistants first extracted data independently from 10 websites and, after comparing their procedures, they wrote a manual to systematize the data extraction process. Next, the reviewers extracted data from 9 other websites to validate the manual's documented procedure. Then, the data extraction tasks from the remaining 23 websites were equally distributed between them.

Thereafter, understandability and actionability of the website content were evaluated using the Patient Educational Materials Assessment Tool (PEMAT) [30] available online [31]. According to this tool, "understandability" refers to the ease in understanding what is written with regard to content, word choice and style, use of numbers, organization, layout and design, and use of visual aids. "Actionability" refers to the ease of putting into action the information presented or implementing it in real life. A single trained evaluator completed the evaluation of the selected websites. The evaluation results included both printable and audiovisual material versions. The scoring process was straightforward for all 26 items: for instance, "the material uses active voice" (item #5) or "the material provides a summary" (item #11). One (1) point was assigned if the item was fulfilled and zero (0) point, if not [31]. The COUNTIF function in Microsoft Excel was used to produce the statistics of the PEMAT scores from our extraction table. The minimum PEMAT score required for a website to be qualified as adequately understood and actionable was 70% [31]. Scores higher than 70% were further categorized as follows: 70%-79%, acceptably understandable and actionable; 80%-89%, easily understandable and actionable; and 90%-100%, perfectly understandable and actionable. One of the PEMAT subcriteria, that is, the presence of instructions or examples to explain how to perform calculations if any, was excluded from further analysis because no occurrence was found.

Results

Of the 42 websites selected for the analysis, 39 (93%) contained information mostly in a textual format, whereas 32 (76%) also used a video format. Moreover, 25 (60%) of the 42 websites used visual aids but most did not considerably enrich the textual content (eg, an image of a father holding a book in his hands with his two children in their bed was placed next to a paragraph describing how to help children with sleep disturbance). The information presented in these websites had been reviewed either by professionals or a scientific or advisory committee for only 18 (43%) websites, whereas information was not verified for 8 (19%) websites. Moreover, we found that 19 (45%) of the 42 websites were updated within the last month, 5 (12%) were updated within the last 1-3 months, 5 (12%) were updated within the last 4-6 months, 1 (2%) was updated within the last 7-12 months, and 5 (12%) had not been updated in the previous year. Information about the last update was not determinable for 7 (17%) of all websites studied.

With regard to the type of disability, 20 (48%) of the 42 websites contained information about ASD and 19 (45%) had information about learning disabilities. Behavioral disorders and developmental language disorder were each discussed in 4 (10%) websites. Mental health issues, including anxiety, bipolar disorder, depression, and eating and personality disorders were discussed in 6 (14%) websites. Other disabilities such as cerebral lesion or palsy, Down syndrome, epilepsy, and spina bifida were discussed in 6 (14%) websites.

With regard to the activity domains of the International Classification of Functioning, Disability and Health, 9 domains were examined: learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social, and civic life [32]. Most the websites addressed topics related to communication (35/42, 83%), learning and knowledge application (33/42, 79%), and relationships and interactions with others (31/42, 74%). Topics pertaining to community, social, and civic life (9/42, 21%); domestic life (12/42, 29%); and mobility (15/42, 36%) were not as frequently covered in the websites examined.

Most websites examined presented tips and advice (37/42, 88%), explanatory material (35/42, 83%), and references to similar or additional resources (32/42, 76%). Printable documents and testimonies were each found in 23 (55%) websites. Moreover, 14 (33%) websites included workshops; activity ideas for development of specific skills; personalized newsletters; or scientific articles, advertisements, questionnaires, and game platforms. Only 7 (17%) of the 42 websites examined offered networking opportunities such as comment boxes, chat, forums, and a “frequently asked questions” zone.

Based on the PEMAT usability evaluation scoring system, 22 (52%) websites received a global score <70%, whereas the remaining 20 (48%) received a score ≥70% (Table S2 in Multimedia Appendix 2).

In the understandability category, 20 (48%) of the 42 websites (Figure 1) scored <70%, whereas 22 (52%) scored ≥70%. In the actionability category, 27 (64%) websites scored <70%, no website scored between 70% and 79%, 6 (14%) scored between 80% and 89%, and 9 (22%) scored ≥90%. When combining understandability and actionability, only 14 websites (33%) websites scored ≥70% in both categories.

Results for the *understandability* subcriterion are presented in Figure 2, where we can see that not many websites scored over 70% for 4 aspects (content: 8/42, 19%; organization: 10/42, 24%; layout and design: 14/42, 33%; and use of visual aids: 9/14, 22%).

Figure 1. Understandability and Actionability scores based on PEMAT evaluation. PEMAT: patient educational materials assessment tool.

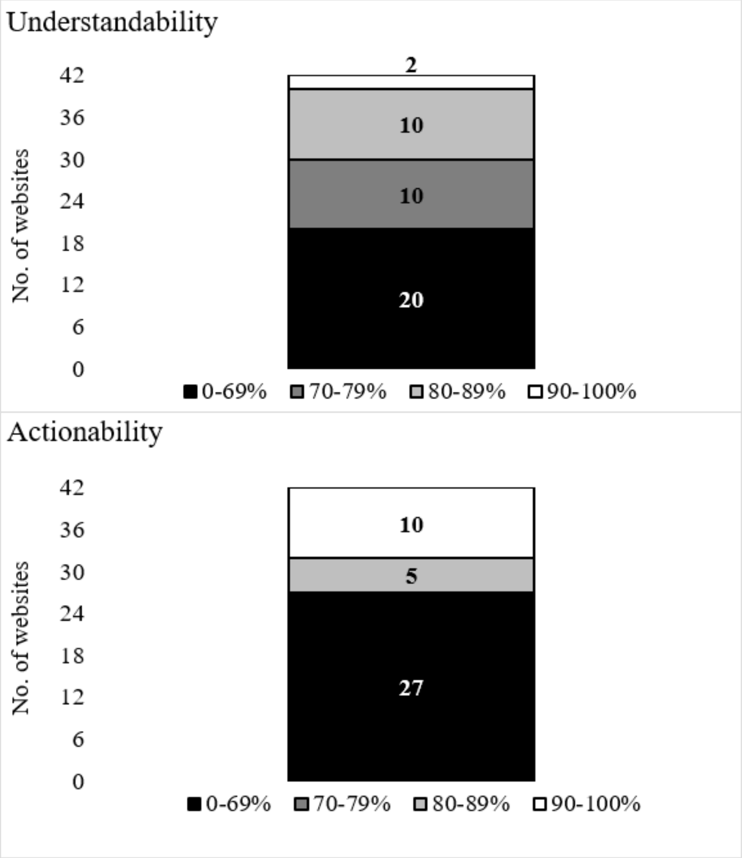
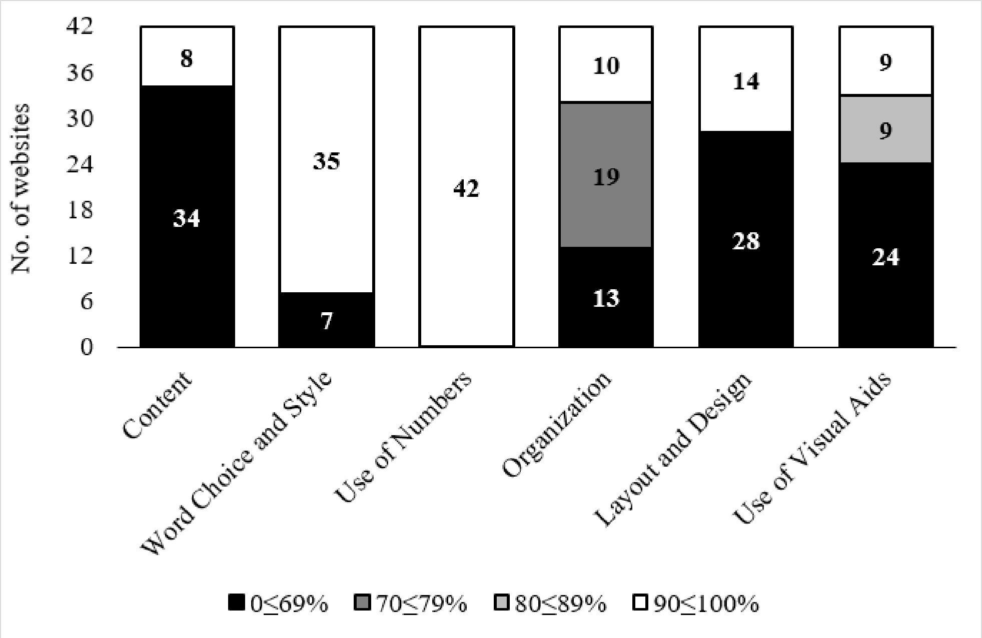


Figure 2. Scores per criteria in the Understandability category.



Discussion

Principal Findings

The objective of this study was to describe the type of information available on the internet for parents of children with disability as well as to assess the understandability and actionability of the web content. As a result, we recorded and studied the descriptive characteristics and PEMAT scores of 42 websites. Of these 42 websites, 39 (93%) presented information primarily in an encyclopedic textual format, which is not the most efficient format according to recently published recommendations [25], and even when websites contained visuals aids, those did not always add to the textual information.

Moreover, more than half of the websites were regarded as insufficiently understandable and actionable according to the PEMAT evaluation. These findings suggest that some parents, especially those of children with a less common disability [33], do not find adequate information on the internet that may help them address all of the child's needs.

The type of information available on websites is mostly written (textual format) and often organized in an encyclopedic style. Although the information on these websites may be useful to the parents, the encyclopedic format is not optimal for fast and effective learning [34,35]. Similar studies have also reported that most websites rarely offer relevant visual aids to support the written information [14,22,36-38]. This finding, however, is not consistent with current technological resources that allow easy integration of multiple formats (audio, video, etc.) into websites. The websites that facilitate the most user-friendly reading experience are those that provide simple and explanatory visual aids and short texts with emphasized keywords (eg, bold characters, different character font and color, and summary boxes).

Our analysis also highlights an important message that direct access to information on the web does not necessarily imply trustable information [39,40]. In fact, approximately 57% of the websites analyzed in this study had information that was not reviewed by professionals or experts prior to publication. Nevertheless, parents searching for information or advice would not necessarily think about the trustworthiness of the source [23], or they may have difficulty determining, with certainty, which information to trust [41,42]. In such cases, people are likely to choose the information that is easier to understand or that better fits their current knowledge and understanding of the topic [43,44]. This situation is potentially problematic because there could be some risk in applying tips that are controversial. For example, a website may be promoting participation in regular physical activity but may not indicate that such activity could be dangerous for a child with epilepsy or severe osteoporosis [45]. To address this problem, we recommend that parents consult websites that publish content that has been reviewed by experts. Informational websites should also consider offering parents an online platform to discuss the content. It could be helpful for some parents to know that other parents found certain information useful and practical in a real-life situation [9,10].

Another disadvantage of more than half of the websites (55%) analyzed was that they were not frequently updated. Unavailability of up-to-date quality content was a perceived concern for 61% of the parents looking for health-related information on the internet [46]; however, other parents reported they did not verify whether the information was current or not. Lack of up-to-date content would imply that obsolete advice may be put into practice. Moreover, parents may not be able to verify information found online in a timely manner during appointments with their health professional team due to time constraints. Furthermore, parents are not necessarily prepared to address all subjects of concern during a clinical appointment [9,17,47]. The internet has thus become parents' source of information for "pressing needs."

More importantly, the content of the websites we analyzed mostly focused on the disability itself instead of on the child's functioning. As a result, these websites only partially address the concerned parents' needs and do not cover the several questions and challenges they may have [17,48]. If it were possible to search for information pertaining to various developmental disorders (eg, sleep problems), access to information that addresses parents' needs might be easier, especially for parents of children with developmental challenges that have not yet received a definitive diagnosis. Our study findings reinforce the importance of having credible websites that are easily accessible and can be adapted to the changing needs and real-time requirements of parents of children with disability.

Finally, we also searched for websites with an added feature for opportunities for networking, but we did not find them among in the websites we examined. However, considering that technology to include such a feature on websites exists and that parents of children with disability express a pressing need for networking, it thus seems timely to consider developing such networking channels for this population.

With regard to the usability of the websites, the results of the PEMAT evaluation showed high variability among the quality of websites. The small proportion of true high scores (white: 2/42, 5%) and the large proportion of moderate (grey: 18/42, 43%) and weak scores (black: 22/42, 52%) can be interpreted as lack of relevant visual aids or clear instructions that aid the users to apply the textual information in their lives. This situation is problematic because it means that users put in place the presented advice without being sure that it is correctly executed.

Limitations and Strengths

First, in coherence with our local context and health policies, one of the limitations of the procedures used in this study was that they were focused on Canadian resources and on French language websites. Second, our study is exploratory in nature because we did not find published recommendations for procedures to conduct the website review in a systematic manner. Thus, we proceeded in an iterative fashion, reflecting at every decisional stage and stopped the review when we concluded that we had reached content saturation.

The most important strength of this study is the patient-oriented research approach. We closely collaborated with two parents, each of whom have children with disability. This ascertains that our results are in line with the preoccupations of our target audience. Second, the juxtaposition of the PEMAT system to our data extraction table allows us to focus on the criteria that ease understandability and actionability.

Conclusions

This study analyzed 42 existing websites on the internet intended for parents of children with disability, with an aim to determine the type of information presented, its usability, and the opportunity for networking available. Our results suggest that there is a need for websites that have expert-reviewed content, to provide accurate and accessible information at least for non–English-speaking parents of children with disability.

Moreover, the results of our study highlight the need to design websites that consider usability and actionability of content or, in other words, provide opportunities for networking.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Descriptive characteristics extracted from the websites analyzed.
[PDF File (Adobe PDF File), 358 KB - pediatrics_v3i2e19669_app1.pdf]

Multimedia Appendix 2
Total Patient Educational Materials Assessment Tool score for each website analyzed.
[PDF File (Adobe PDF File), 293 KB - pediatrics_v3i2e19669_app2.pdf]

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Abbreviations

ASD: autism spectrum disorder
PEMAT: Patient Educational Materials Assessment Tool

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Original Paper

Social Media Use Among Young Adults With Connective Tissue Disorders: Cross-Sectional Pilot Study

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Abstract

Background: Young people with genetic conditions often face challenges coping with their health condition. It can be difficult for them to meet someone with a similar condition, which is important for reinforcement of chronic illness management recommendations. Social media is used by 97% of young people in the United States and may provide those with these disorders a space for emotional expression and support. However, there is a scarcity of literature related to the use of social media among adolescents with genetic conditions as an indicator of their perception regarding their own condition.

Objective: The purpose of this pilot study was to obtain preliminary data to assess and understand social media use by young people with connective tissue disorders and determine whether they use social media to connect with patients with similar conditions or whether they would be interested in doing so.

Methods: We undertook a pilot study of selected connective tissue disorders occurring in young people between the ages of 11 and 25 years, including Marfan syndrome; Ehlers-Danlos syndrome subtypes classical, classical-like, cardiac-valvular, and vascular; Beals congenital contractual arachnodactyly; and Alport hereditary nephritis. The study took place within one pediatric clinical system. Patients were identified through electronic medical record search and International Classification of Diseases, Ninth Revision, coding at a Midwest university–based clinical system. Study subjects completed a short survey describing their experiences with their connective tissue disorders, their means of self-expression, their existing network of persons to communicate with, and their use of social media. Data analysis included nominal and bivariate regressions to compare social media use in relation to age.

Results: Our 31 participants (42% response rate) were 55% female (17/31) and their average age was 18 years (SD 5). All participants used social media and there were no statistically significant differences between social media use and age. The majority of participants (25/30, 83%) reported that they never used social media to discuss their condition (P=.09), and only 17% (5/30) knew someone online with a similar condition (P=.50). Most participants (19/30, 63%) said they would communicate with someone with a similar disorder (P=.64).

Conclusions: We found that young individuals with connective tissue disorders use at least one type of social media. A majority did not use social media to discuss their condition or know someone online with a similar condition. However, many persons were interested in finding others similarly affected. Social media could serve as a platform for young people with connective tissue disorders to connect. Peer support is important in disease management and adolescent development. Future studies should aim at understanding social media use among young people with connective tissue disorders and helping them connect with other people who have similar conditions.

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KEYWORDS

connective tissue disorders; social media; adolescents; young adults; Marfan syndrome; Ehlers-Danlos syndrome; Alport hereditary nephritis; Beals congenital contractual arachnodactyly; internet

Introduction

Connective tissue disorders refer to a group of uncommon and heterogeneous conditions that are associated with pathogenic defects in the extracellular matrix [1-6]. As a consequence of these defects, affected individuals may have alterations in the development of bone, skin, vasculature, and other related organs [1-6]. A majority of connective tissue disorders are inherited in an autosomal dominant fashion [1-6].

Living with a genetic condition can lead to feelings of stigmatization and emotional pain due to being different from peers, in addition to social, emotional, and financial stress [7-9]. In particular, young adults with chronic illnesses often experience more social isolation compared to their peers [7]. Young people with Marfan syndrome have reported “difficulties in keeping up with peers” in school, sports, activities, relationships, and work because of their condition [9]. Time-consuming medical visits and treatments, fatigue, pain, and fear of injury were contributing factors to the difficulties associated with “keeping up with peers” [9]. Young people with Marfan syndrome also feel different from their peers due to their appearance, fatigue, pain, and disability. Many individuals with connective tissue disorders have to limit physical activities and sports to prevent life-threatening injuries [1-5]. Some adolescents and young adults experienced bullying, and individuals with lower self-esteem were more likely to avoid social activities, such as going to the beach or parties [9]. Previous research has found that having Marfan syndrome can lead to a lower quality of life mentally, due to emotional and psychological impairment [8-10].

Social media is used by 97% of US youth [11] and is recognized as an influential determinant of their health maintenance [12-14]. Social media can be used as an outlet to display people’s feelings and experiences regarding a health condition as well as foster social connection [14-16]. Additionally, social media makes it possible for teens to connect with new friends as well as maintain existing friendships [15,16]. The Pew Research Center found that 57% of teens between the ages of 13 and 17 years have made a new friend online [15].

Currently, social media sites provide support groups and/or posts for patients with connective tissue disorders included in this study. Posts and groups can be found by searching for the connective tissue disorder via the search bar on a social media site. There are groups and posts related to the more prevalent connective tissue disorders, such as Marfan syndrome and Ehlers-Danlos syndrome (Ehlers-Danlos), on Facebook, Twitter, Reddit, and Tumblr [17-20]. Less prevalent conditions, such as Alport hereditary nephritis (Alport syndrome) and Beals congenital contractual arachnodactyly (Beals syndrome), maintain smaller circles and have posts and groups on Facebook, Twitter, and Reddit [17-20].

Previous research has provided evidence that communicating about one’s condition can help individuals cope with their diagnosis, increase knowledge about their condition, and increase involvement in their own medical care [9,21-23]. Individuals with chronic illnesses who use social media to share and exchange information and experiences report an “enhanced feeling of self-worth and validation, often inhibited by living with chronic illness” [23]. For a majority, providing and receiving support through social media can decrease feelings of isolation and loneliness by bringing people together, especially when someone is not feeling well [23]. One individual with chronic pain explained, “social network sites have allowed me to have a social life...when the pain is bad, which is frequent, I cannot leave my house and spend time with friends” [23]. However, some individuals report that social media can have a negative impact due to feelings of withdrawal or frustration [23].

There is an increase in social media use among individuals with chronic illnesses to connect with others similar to them and learn information regarding their condition [12,13,24]. However**,** most young people with chronic conditions are particular about the content they publicly share on their social media accounts regarding their chronic condition [23,25,26]. Some adults with chronic illnesses feel a sense of control and an increase in self-worth when posting about their condition on social media, while others worry about the psychological and physical consequences of sharing personal information publicly [23].

Although a majority of young people receive positive feedback when posting about their condition, many chose not to post about their condition because they fear stigmatization and rejection [25,27]. Currently, there is a scarcity of literature regarding the number of young people with rare chronic illnesses that use social media to communicate about their condition.

Due to the rarity of connective tissue disorders, it can be challenging to meet other individuals with similar conditions. Social media allows users to find support globally by decreasing geographical and time barriers [23]. Some even use social media to connect individuals with health care providers around the world [23]. This is important for the treatment of individuals with rare conditions who do not have a specialist for their condition in their area. A prior study investigating Marfan syndrome social media references found that a majority of posts displayed personal experiences and symptoms regarding Marfan syndrome [28]. This study also found that Marfan syndrome was discussed across different public social media platforms. However, there is a scarcity of literature related to the use of social media among young people with genetic conditions as a window to their perception regarding their own condition. Based on this previous study, we hypothesized that young people with connective tissue disorders used social media to communicate their perceptions, experiences, and concerns regarding their condition.

The purpose of this pilot study was to obtain preliminary data to assess social media use, understand how social media was used, and determine whether patients with connective tissue disorders use social media to connect with other individuals with similar conditions or whether they would be willing to do so. With the understanding of how young people with selected connective tissue disorders communicate online, future research can be done on improving online support, since online communication keeps growing.

Methods

Overview

This cross-sectional pilot study was approved by the University of Wisconsin Health Sciences Institutional Review Board and took place from September 2013 to May 2015. The data were collected and analyzed at the University of Wisconsin-Madison, School of Medicine and Public Health, in the Department of Pediatrics, Division of Genetics and Metabolism.

A prior content analysis study investigating Marfan syndrome social media references found references to Marfan syndrome across public social media platforms, such as Instagram, Pinterest, Reddit, Tumblr, and Twitter [28]. However, there is a scarcity of literature regarding how young people with chronic genetic conditions, such as connective tissue disorders, use social media with regard to their condition.

Participants

We identified young people between the ages of 11 and 25 years with connective tissue disorders, including Marfan syndrome, Ehlers-Danlos, Alport syndrome, and Beals syndrome; see Table 1 [1-6] for connective tissue disorder characteristics. Ehlers-Danlos subtypes include classical, classical-like, cardiac-valvular, and vascular Ehlers-Danlos. These connective tissue disorders were chosen due to their association with significant medical consequences.

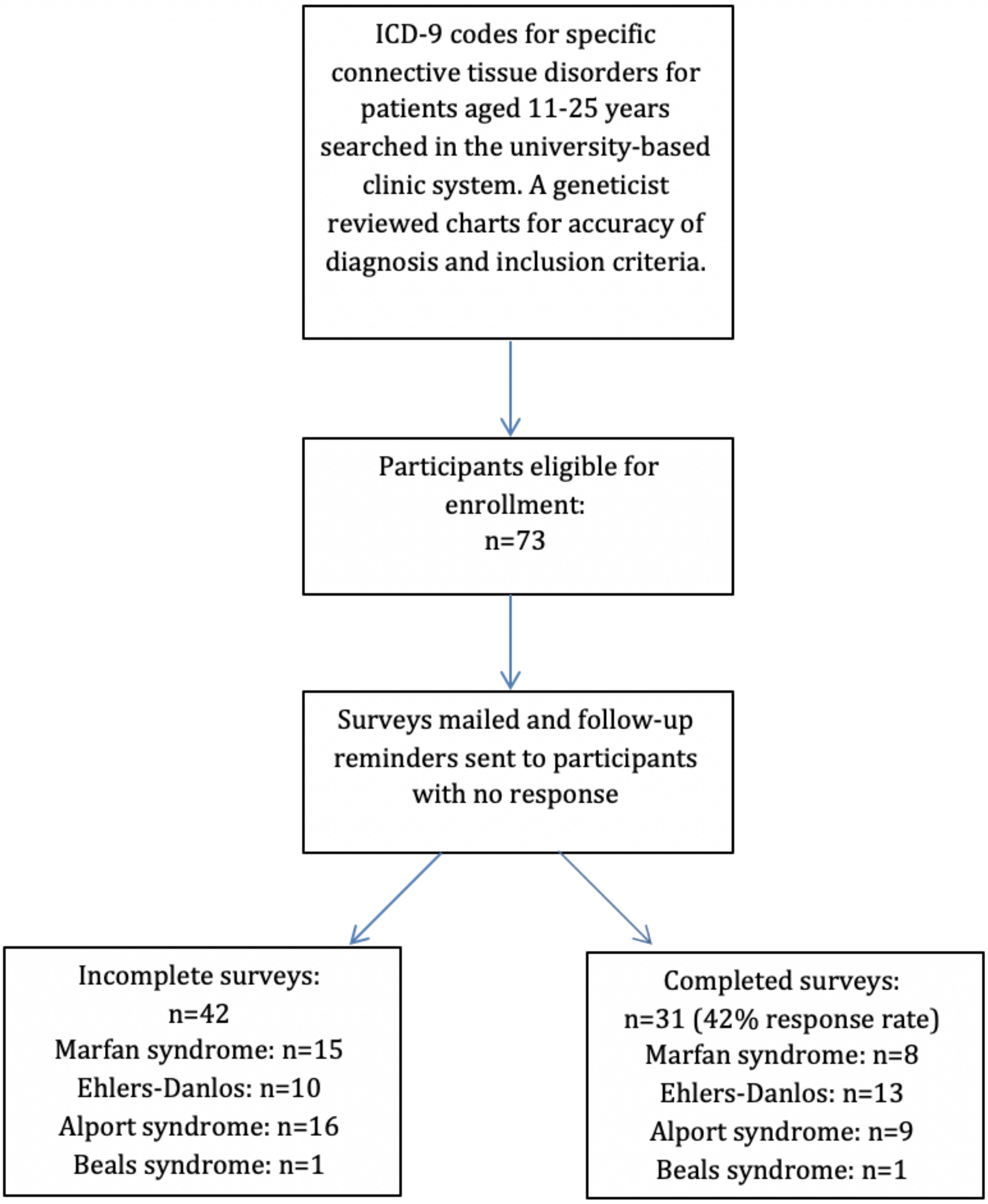
Table 1. Summary of connective tissue disorders and associated features.

Condition (gene)	Worldwide prevalence	Non-life-threatening features	Life-threatening features	Key references
Marfan syndrome (FBN1)	1:5000-1:10,000	Tall stature Scoliosis Pectus excavatum or carinatum Lens dislocation Flat feet	Aortic root enlargement and dissection	[1]
Ehlers-Danlos syndrome[a] (COL5A1, COL5A2, and COL3A1)	Classical: 1:20,000 Vascular: 1:50,000-1:200,000	Joint hypermobility Joint pain Soft velvety and/or elastic skin Easy bruising and poor wound healing	Aneurysms throughout the vascular tree (vascular subtype)	[2-4]
Alport hereditary nephritis (COL4A5)	1:50,000	Hearing loss Eye abnormalities (lenticonus) Edema in extremities	Loss of kidney function resulting in kidney failure	[6]
Beals congenital contractual arachnodactyly (FBN2)	Unknown	Contracted joints Scoliosis Crumpling of ear Pectus excavatum or carinatum Long, tall stature Mild aortic root enlargement	Aortic dissection (rarely seen) Rare, lethal cases can result in severe cardiovascular and gastrointestinal symptoms	[5]

[a] Combination of the four types: classical, classical-like, cardiac-valvular, and vascular Ehlers-Danlos syndrome; the prevalence for classical-like and cardiac-valvular Ehlers-Danlos syndrome is unknown.

Participants were queried in the University of Wisconsin Hospital and Clinics electronic medical record to identify patients who were classified in the different connective tissue diagnosis categories; see Figure 1 for the methods flowchart. The following information from medical records was reviewed by a coauthor and clinical geneticist (PG) for accuracy of diagnosis and qualification for enrollment in the study: medical complications related to connective tissue disorders related to the eye, heart, body skeleton, vascular system, skin, and spine as well as DNA testing that validates the diagnosis of Marfan syndrome and related connective tissue disorders. Charts were reviewed for patients between the ages of 11 and 25 years with Marfan syndrome; Loeys-Dietz syndrome; Ehlers-Danlos subtypes classical, classical-like, cardiac-valvular, and vascular; MASS (mitral valve, myopia, aorta, skin, and skeletal features) phenotype; Stickler syndrome; Alport syndrome; Beals syndrome; and dystrophic epidermolysis bullosa, regardless of gender and ethnicity. The patients with Loeys-Dietz syndrome, MASS phenotype, Stickler syndrome, and dystrophic epidermolysis bullosa with International Classification of Diseases, Ninth Revision (ICD-9) diagnosis codes did not meet the diagnostic criteria for the condition and, therefore, were excluded from this study. After reviewing medical charts, 72 patients met the inclusion criteria. All patients that met the study requirements were approached for possible enrollment.

Figure 1. Study methods flowchart. Alport syndrome: Alport hereditary nephritis; Beals syndrome: Beals congenital contractual arachnodactyly; Ehlers-Danlos: Ehlers-Danlos syndrome; ICD-9: International Classification of Diseases, Ninth Revision.



Survey Instrument

We reviewed previous literature to identify validated questions to assess social media use and created a self-developed survey [29]. The categories were developed with an adolescent health physician, a clinical geneticist, and adaptations from a Pew Research Center study [29]. In 2010, the Pew Research Center asked adolescents and young adults about social networking sites, gaming, and creative websites. We separated photo and video sharing from the Pew Research Center’s creativity section. Instagram was created in 2010 and, therefore, was not included in the Pew Research Center report. We felt that it was an important platform to include. We also wanted to include music sharing in the survey. The survey was piloted to genetic counselors at the institution and feedback was provided. The survey categories included the following: demographics, personal life (eg, hobbies, self-expression, and goals), basic information about their connective tissue disorder (eg, age of diagnosis, surgery and medication, and concerns), and social media use. To assess social media use, we asked participants about the number of hours per week spent on specific types social media sites; see Multimedia Appendix 1 for the survey.

The categories of social media included, and were described as, social networking sites (eg, Facebook, Twitter, etc), online gaming (eg, World of Warcraft), music sharing (eg, Pandora), video sharing or streaming (eg, YouTube and Hulu), photo sharing (eg, Instagram), and creative sites (eg, Pinterest and Tumblr). To understand how social media was used, we asked an open-ended question about how participants used social media. To determine whether participants used social media to connect with others with similar disorders, we asked participants about the frequency with which they discussed their condition and whether they received support from posting about their condition. To determine whether participants were willing to connect, we asked whether and how they would like to communicate with someone similar to them online.

Recruitment

A data security analyst reviewed the electronic medical record to identify patients with connective tissue disorders. A clinical geneticist then reviewed records of potentially eligible patients to validate their fulfillment of the clinical criterion of having one of the connective tissue disorders being studied. Each patient was assigned a study code. After surveys were complete, the document linking the name of the patient with the study number was destroyed. All clinical data were kept under lock and key, and only the principal investigator and research assistant had access to the study.

A letter inviting each patient to participate in the study was signed by one of the patient’s physicians who participated in care for his or her underlying connective tissue disorder. Along with the letter, a consent and assent document, a survey, and a stamped and addressed return envelope were then mailed to the patient and their family. Participants who did not respond received a follow-up phone call several weeks after the initial letter of invitation. A follow-up letter and phone call was sent to participants several weeks after the first phone call. Participants were subsequently reminded about the study and informed that they could opt to take the survey on the phone. If there was no response, two additional follow-up letters were mailed home after the phone call. If at that time there was no response, no further contact was attempted.

Data Analysis

Survey responses were recorded in a Microsoft Excel 2007 spreadsheet as a secure file on a protected server. Surveys were analyzed to determine descriptive outcomes described above. Survey questions that were not answered were not included in the analysis. Due to the wide age range and small sample size, responses between participants of differing connective tissue disorders were grouped together and analyzed by age group. The following categories were created: early adolescents (11-14 years), middle to late adolescents (15-21 years), and young adults (22-25 years) [30]. Data were analyzed using SPSS Statistics for Windows, version 26.0 (IBM Corp) [31]. A nominal regression was conducted to assess the relationship between age and whether participants would like to communicate with someone with a similar condition. Separate bivariate logistic regressions were used to analyze the relationship between age and discussing questions and concerns on social media, age and knowing someone offline, and age and knowing someone online. A Pearson correlation was calculated to determine the strength of the relationship between age and discussion of questions or concerns on social media.

Results

Participants

Of the 73 surveys sent to eligible patients, 31 surveys were completed and returned (42% response rate). The average age of nonrespondents was 18.4 years (SD 4.0), with a median age of 19 years. Among respondents who completed surveys, 55% (17/31) were female and 90% (28/31) were Caucasian, with an average age of 18 years (SD 5); see Table 2 for demographic characteristics. Out of 31 participants, 2 (6%) were Mexican and 1 (3%) was Lebanese. Over a quarter of the sample (9/31, 29%) were early adolescents, 35% (11/31) were middle to late adolescents, and 35% (11/31) were young adults. Only 2 participants out of 31 (6%) completed the survey over the phone. Out of 31 participants, 1 (3%) did not answer questions regarding social media use and was not included in the social media analysis.

Table 2. Demographic characteristics of the participants.

Characteristic	Early adolescents (n=9)	Middle to late adolescents (n=11)	Young adults (n=11)	Total (N=31)
Gender, n (%)				
Male	4 (44)	5 (45)	5 (45)	14 (45)
Female	5 (56)	6 (55)	6 (55)	17 (55)
Age (years)				
Mean (SD)	13 (1)	17 (2)	24 (1)	18 (5)
Median	13	17	24	17
Race, n (%)				
White	7 (78)	10 (91)	11 (100)	28 (90)
Other	2 (22)	1 (9)	0 (0)	3 (10)

Survey

All participants indicated using at least one type of social media and 97% (29/30) used more than one type of social media. The most common social media types used were social networking sites (24/30, 80%) and video sharing (25/30, 83%). Creative sites (6/30, 20%), online gaming (8/30, 27%), music sharing (15/30, 50%), and photo sharing (15/30, 50%) were less popular social media sites. Although participants were not asked to specify which specific sites they used, Facebook, Twitter, Instagram, and YouTube were mentioned by participants throughout the survey. The most common way participants used social media was to maintain relationships (19/30, 63%), learn new information (7/30, 23%), and watch entertaining videos and photos (7/30, 23%).

There were no statistically significant differences in social media use based on age—age and discussion of questions or concerns about condition on social media: *r*=.32, *P*=.09 (N=30); age and knowing someone offline: χ^2_1=1.1, *P*=.30 (N=30); age and knowing someone online: χ^2_1=0.5, *P*=.50 (N=30); and age and wanting to communicate with someone: χ^2_1=0.9, *P*=.64 (N=30). Although there was statistical significance between age and frequency of posting online, there was a medium to moderate correlation. With a larger sample size, we hypothesize there could be a statistical significance in the frequency of posting about one's condition at different ages.

Over one-third (11/30, 37%) of participants communicated their condition with a family member, 23% (7/30) with a health care professional, and 13% (4/30) with anyone (see Table 3). Only 17% (5/30) of participants discussed their questions and concerns on social media and 17% (5/30) used social media to communicate with someone with a similar condition. Only middle to late adolescents and young adults discussed concerns or communicated about their condition online. Of note, 3 of the 5 participants (60%) that discussed their condition on social media also used social media to communicate with someone with a similar condition. Over half (16/30, 53%) of participants knew someone with the same or a similar condition offline and only 17% (5/30) knew someone online with a similar or the same condition. Only 2 participants out of 30 (7%) knew someone both online and offline with a similar condition. However, 63% (19/30) of the participants answered that they would communicate with someone with a similar condition if they had the opportunity. Of those participants, 84% (16/19) suggested email or social media as a potential means of communication. Other suggestions included talking and meeting in person (6/19, 32%).

Ehlers-Danlos participants were the only 5 participants out of 30 (17%) that posted about their condition online, and all of them received support at least some of the time (3/5, 60%) or a majority of the time (2/5, 40%). A majority (4/5, 80%) of these participants that posted about their condition also knew someone online and communicated through email and texting.

Table 3. Online and social media survey results.

Question and responses	Early adolescents[a] (n=9), n (%)	Middle to late adolescents (n=11), n (%)	Young adults (n=11), n (%)	Total (N=30), n (%)
Who do you feel most comfortable talking to with regard to your condition?				
Family	4 (44)	2 (18)	5 (45)	11 (37)
Health care professional	1 (11)	4 (36)	2 (18)	7 (23)
Friend or significant other	1 (11)	2 (18)	1 (9)	4 (13)
Anyone	1 (11)	1 (9)	2 (18)	4 (13)
No one	0 (0)	1 (9)	0 (0)	1 (3)
Other	2 (22)	2 (18)	1 (9)	5 (17)
Do you discuss your questions or concerns about your condition on social media?				
Never	8 (89)	9 (82)	8 (73)	25 (83)
Rarely	0 (0)	1 (9)	0 (0)	1 (3)
Sometimes	0 (0)	0 (0)	3 (27)	3 (10)
Always	0 (0)	1 (9)	0 (0)	1 (3)
Do you use social media to communicate with people with similar conditions as you?				
No	8 (89)	8 (73)	9 (82)	25 (83)
Yes	0 (0)	3 (27)	2 (18)	5 (17)
Do you know anyone else from offline with the same or similar conditions?				
No	3 (33)	6 (55)	7 (64)	16 (53)
Yes	5 (56)	5 (45)	4 (36)	14 (47)
Do you know anyone else from online websites with the same or similar conditions?				
No	7 (78)	9 (82)	9 (82)	25 (83)
Yes	1 (11)	2 (18)	2 (18)	5 (17)
If you could, would you communicate with someone with the same or similar conditions?				
No	2 (22)	2 (18)	3 (27)	7 (23)
Maybe	1 (11)	1 (9)	2 (18)	4 (13)
Yes	5 (56)	8 (73)	6 (55)	19 (63)

[a] One participant did not answer all questions.

Discussion

Principal Findings

This study examined social media use of young people with connective tissue disorders. We ascertained that all of the participants used social media, and a majority used more than one type of social media site. Participants used social media to connect with friends and family, to learn new information, and as a source of entertainment. These findings support previous studies regarding social media use and motivations in young people without chronic conditions [15,16,32].

Young, middle, and older adolescents and young adults used social media similarly. A majority of young people utilized offline relationships, such as family or health care providers, rather than social media to discuss their concerns or questions regarding their condition. Early adolescents did not use social media to discuss their condition or communicate with other individuals with similar conditions. This supports a previous study that found that healthy young people aged 12-14 years were less likely to post about their health on social media compared to older adolescents and young adults [32]. Middle to late adolescents and young adults with Ehlers-Danlos were the only participants who used social media to discuss their condition.

A majority of participants that posted about their condition also used social media to communicate with someone with a similar condition. One explanation could be that individuals who have friends with similar conditions online may feel more comfortable posting about their condition. If young people see peers posting about their condition online, it may encourage them to post about their own condition. Participants who chose to post about their condition described receiving positive feedback from their online interactions. Previous studies have also found that positive feedback is received among the majority of the few young adults with chronic illnesses that post about their condition [25,27].

Social media allows users to communicate intimately and immediately, which has been shown to be an important component in social support [27]. Many individuals with chronic illnesses prefer to seek social support from someone with a similar illness [25,27]. Social media sites offer unprecedented opportunities for this type of support [23,25,27]. In order to successfully intervene with young people with connective tissue disorders to improve social connections, it is important to learn about the different ways young people use social media in regard to their condition. It is possible that young people with connective tissue disorders do not want to publicly post about their condition, but would be more willing to communicate about their condition in an anonymous or private way via private chatting or anonymous usernames [23]. Many young people with chronic illnesses are protective of their health information and do not disclose their health to extended family members and peers that are not close friends [25]. Therefore, many might not be comfortable publicly posting about their condition online.

Almost half of participants did not know another individual with a similar condition in their offline or online lives. However, we found a majority of participants were interested in communicating with other individuals with connective tissue disorders via email or social media. Our findings were consistent with previous studies that found that young people with chronic illnesses use social media, but not to discuss their condition [25,26]. Yet, a majority were interested in discussing their condition online with peers with similar conditions [25,26]. Young people may be more willing to meet individuals through social media in a private setting without sharing their health information with their entire social media circle [23]. Although we did not specifically inquire, a follow-up to this study could be to identify what would be necessary for these young people to connect with others regarding their disorder via social media.

We found that a majority of young people did not post about their condition online. This may be because many young people are scared of facing rejection, pity, or isolation when discussing their chronic condition online [25]. Previous research has found that few young people received negative feedback when posting online [25]. Perceived stigma felt by individuals with chronic disease can affect their willingness to post about their condition online [25]. Young adults are selective in the information they share and many want to seem like “regular young adults” among peers [26,32].

Young adults without chronic conditions are also concerned about their privacy when posting about their health on social media [32]. However, unlike young people with chronic conditions, healthy individuals are more likely to post about their health on social media [32]. Mood was the most common health topic discussed, followed by wellness and acute medical conditions [32]. These topics were discussed with the intention of finding peers with similar conditions, seeking advice, and receiving support [32].

Individuals with Marfan syndrome and related connective tissue disorders were polled at the 2019 Marfan Foundation Annual Conference about their favorite way to keep in touch with the Marfan syndrome and related connective tissue disorders community, and the majority of patients prefer communication through Facebook (unpublished data, 2019). This seems to be inconsistent with the survey findings reported in this communication. We speculate that patients feel less motivated to discuss their specific cases but are willing to discuss concerns related to the Marfan community as a whole using social media.

Due to the variety of social media platforms, it seems possible for individuals to find the type of connection or support they want without exposing their condition publicly. Different platforms offer varying levels of anonymity and different types of content. Platforms such as Reddit, Tumblr, and Twitter offer greater anonymity compared to Facebook. One way individuals are able control how much information is shared on their social media profiles is through privacy settings. In one study regarding social media use in teens with chronic illnesses, teens reported that they regularly check their privacy settings and feel confident in their privacy settings [26]. Having a sense of control over what information is shared is important to many young people with chronic illnesses [26]. Young people that post about their condition online have emphasized that they feel as though they are in control of what is shared [26].

Previous research has demonstrated that building relationships and networking with other individuals with a similar disorder has psychological and emotional benefits for people with connective tissue disorders [9,21-23,26]. Many young people do not think social media is helpful in obtaining health information [32]. Therefore**,** young people may prefer social media platforms that allow users to develop relationships and communities rather than sites that provide educational content. However, further research is needed to understand what barriers teens face or what processes would be helpful to connect them to others via social media.

Several studies have highlighted the importance of support among individuals experiencing stigmatization due to chronic illnesses [7,9,25,33,34]. A previous study found that 1 in 4 (25%) internet users with a chronic illness have gone online to find someone with a similar condition [35]. Peer support can increase peer interaction and participation and also offer authentic empathy and validation that professionals may not be able to offer [7,9,23,34]. Due to the rarity of connective tissue disorders, meeting someone offline with a similar condition may be challenging [1-6]. Social media could be used to overcome this challenge and bring together individuals with connective tissue disorders.

Young people without chronic illnesses use social media to meet new people with similar interests and maintain friendships [16]. Individuals with connective tissue disorders can use social media to identify other individuals with similar experiences [28]. However, young people with chronic conditions are less likely to publicly post about their condition and experiences on social media, which could make it difficult to find peers with similar conditions [25,26]. Young people with connective tissue disorders may need help finding spaces where they can connect with peers while maintaining their privacy regarding their condition.

Limitations

This study has several limitations. This pilot study was conducted from 2013 to 2015. The internet and social media are constantly changing and, therefore, social media patterns in this study may be different than current social media trends. This study was performed using a single hospital network. Our study was composed of a small sample size of individuals with a limited number of connective tissue disorders. A majority of the sample was Caucasian and, therefore, results cannot be generalized to all individuals with connective tissue disorders. We realize there is clinical genetic heterogeneity among these conditions, especially among the Ehlers-Danlos subtypes. Future studies should be aimed at surveying young people among the different Ehlers-Danlos subtypes. It is also possible that there was selection bias in this sample population. However, regardless of race, ethnicity, and socioeconomic status, a majority of young people are on social media already and are, therefore, familiar with using it [16]. Despite these limitations, social media relationships are becoming more common in young people and, therefore, could be used to form relationships for young people with connective tissue disorders [15].

Future Studies

In this pilot study, we did not directly survey why participants may have chosen not to communicate online about their diagnosis or whether they passively use social media in regard to their condition. Future research can address possible reasons for this, such as lack of participation with health care professional–approved sites, lack of patient interest, or passive social media use, etc. Future studies may also address what would be necessary in order for patients to use social media as a vehicle to communicate individual perceptions regarding their condition. Further research efforts should focus on whether young people would be interested in private social media settings to meet and interact with peers. Future studies could also focus on comparing adults and children with genetic conditions and their social media use.

Conclusions

Although there are social media spaces for individuals with connective tissue disorders to post on and follow, we found that a majority of young people in this study did not use social media to discuss or communicate with others about their genetic condition. However, a majority of participants were interested in communicating with individuals with similar conditions. Due to the rarity of connective tissue disorders, many young people do not know someone with a similar condition. For many individuals, having social support can be instrumental in coping with a chronic illness. Peer mentorship regarding a chronic disease not only aids in disease management and social isolation reduction, but is also a positive factor for adolescent development.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey mailed to participants.
[DOCX File , 19 KB - pediatrics_v3i2e16367_app1.docx]

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Abbreviations

Alport syndrome: Alport hereditary nephritis
Beals syndrome: Beals congenital contractual arachnodactyly
Ehlers-Danlos: Ehlers-Danlos syndrome
ICD-9: International Classification of Diseases, Ninth Revision
MASS: mitral valve, myopia, aorta, skin, and skeletal features

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Original Paper

The Impact of a Smartphone App on the Quality of Pediatric Colonoscopy Preparations: Randomized Controlled Trial

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Abstract

Background: Smartphone apps have been successfully used to help adults prepare for colonoscopies. However, no study to date has investigated the effect of a smartphone app on pediatric colonoscopy preparation.

Objective: The aim of this study is to determine if an app (*SB Colonoscopy Prep*) designed to educate and guide patients through their colonoscopy preparation will yield benefits over paper-based instructions and information.

Methods: In total, 46 patients aged 5-18 years received either app-based or written material with instructions on how to take their prep medications as well as information about the colonoscopy procedure. Prep quality, the number of calls to the gastroenterology service, and patient arrival time were recorded. After the procedure, a questionnaire was given to each patient through which they graded their knowledge of the procedure both before and after receiving the app or written material.

Results: App users had higher mean Boston scores versus control subjects receiving written instructions (7.2 vs 5.9, P=.02), indicating better colonoscopy preps. In total, 75% (15/20) of app users and 41% (9/22) of written instruction users had preps categorized as "excellent" on the Boston scale. We found no significant differences in knowledge about the procedure (app users: 10/20 [50%], written instruction users 8/22 [36%]; P=.37), phone calls to the gastroenterology clinic (n=6 vs n=2; P=.27), or arrival times at the endoscopy suite (44 min vs 46 min before the scheduled procedure time; P=.56).

Conclusions: Smartphone app use was associated with an increased number of colonoscopy preps classified as "excellent" on the Boston scale. There was no significant difference between app users and the control group regarding the number of calls to the gastroenterology clinic, patient arrival time, or patient knowledge about the procedure.

Trial Registration: ClinicalTrials.gov NCT04590105; https://clinicaltrials.gov/ct2/show/NCT04590105

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KEYWORDS

colonoscopy; app; pediatrics; prep; smartphone; mobile phone; mHealth

Introduction

Pediatric colonoscopy is integral for diagnosis and treatment of a number of pediatric gastrointestinal conditions including hematochezia, inflammatory bowel disease, and colonic polyps. Up to one-third of children undergoing these procedures are reported to have suboptimal colon preparation [1]. Poor-quality preparation can increase the risk and length of the procedure, the rate of missed diagnosis, and the cost of the procedure if it is repeated or rescheduled. Studies in adult patients from Pillai et al [2], Hayat et al [3], and Park et al [4] have shown that video-assisted instructions are superior to verbal or standard paper instructions for cleanout quality.

Studies by Lorenzo-Zúñiga et al [5] and Kang et al [6] have shown that instructions delivered via interactive smartphone apps provide superior preparation for adult patients undergoing colonoscopy prep. Health care apps have been successfully used in other fields of medicine, including apps for asthma control [7] and smoking cessation [8].

We created a smartphone app (*SB Colonoscopy Prep*) that informs patients about their colonoscopy procedure, alerts them when to take their medications throughout the hours-long colonoscopy prep process, and tells them when to arrive at the endoscopy suite. We designed a study to determine if this app will yield improved colonoscopy cleanouts, better patient understanding of the procedure, fewer calls to the gastroenterology (GI) clinic, and more punctual arrival times to the endoscopy suite compared to patients who receive noninteractive written instructions.

Methods

In total, 46 patients aged 5-18 years scheduled to undergo a diagnostic and/or therapeutic colonoscopy were recruited for the study. Subjects were volunteers recruited from Stony Brook Children's Hospital's pediatric GI service who were already scheduled to have a colonoscopy.

Exclusion criteria included patients who had undergone a colonoscopy within the past 1 year, patients admitted for a nasogastric cleanout, patients requiring colonoscopy preparation medication other than polyethylene glycol, or patients with a poor understanding of English. Subjects who had undergone a colonoscopy within the previous year were excluded as their prep quality may be influenced by information gathered from their previous procedure rather than the instructions provided to them in our study. Ownership of a smartphone was not required for inclusion in this study. A device was made available for subjects if they did not have a smartphone.

With a grant provided by NASPGHAN (North American Society for Pediatric Gastroenterology, Hepatology and Nutrition), we developed, to our knowledge, the first pediatric-focused smartphone app (that is also compatible for use on a tablet) aimed to help children and their parents prepare for a colonoscopy. The app delivers the same content as the written colonoscopy preparation instructions previously given to patients at our institution but utilizes the advantages inherent to an interactive, multimedia, and patient-operated app.

Subjects were assigned via block randomization to receive either app-based (intervention) or written (control) prep instructions. Subjects in the control group were given a 3-page document that described the procedure and instructed users on how to take the preparation medications. Both groups were provided with an identical list of frequently asked questions about colonoscopies. A link to a website where users could view an animated video was included in the written instructions. The written instructions also contained the time and date of the procedure. All subjects were instructed to arrive 1 hour before their scheduled procedure.

For their colonoscopy prep, patients in both the intervention and control groups were instructed to first take bisacodyl at a specified dosage. Following the bisacodyl, they took a specified amount of polyethylene glycol and mixed it into a specified amount of liquid. Patients drank half of the mixture over 4 hours, took a 2-hour break, and then finished the second half of the prep over the course of another 4 hours. Specific dosages of bisacodyl and polyethylene glycol were based on the patient's weight.

Patients in the intervention group downloaded a free app from the iOS App or Google Play stores called *SB Colonoscopy Prep*. Upon opening the app, users were directed to a home screen containing 8 icons (Figure 1). Users began by clicking the "Start Here!" icon, introducing them to the app and its functions. "Medication Instructions" contains the same instructions the control users received via paper format. "Interactive Prep" walks the patient through the colonoscopy prep process in real time, reminding them what medications to take and when to take them. Subjects received either an audible or vibrating alarm on their smartphones alerting them when it was time to take a new medication, when to take a 2-hour break, and when their prep was complete. For simplicity, the app only provides instructions pertaining to the most commonly used colonoscopy preparation medications at our institution (ie, bisacodyl and polyethylene glycol). "Video Tutorial" contains a short, animated video of a young boy walking the patient through the colonoscopy process using easy-to-understand vocabulary (Multimedia Appendix 1). The boy explains what a colonoscopy is, why prep is important, and what patients can expect when they arrive at the colonoscopy suite. The video also features an animated, smiling colonoscope named "Scopey" designed to be a lighthearted but accurate portrayal of the colonoscopy procedure itself (Figure 2). The video was written and directed by authors DL and BD and animated by CI Design.

"My Colonoscopy" gives users the time and date of their procedure as well as instructions to arrive 1 hour prior to their procedure. Patients are provided with driving, walking. or public transportation directions to our institution. Directions were generated using Google Maps and the patient's current GPS location. Before generating directions, the smartphone asked subjects to grant permission to allow the app to access the user's current location. "Weight & Date" allows users to enter their weight and time and date of their colonoscopy. "FAQs" provides a list of frequently asked questions. Lastly, "Credits" lists the people and institutions responsible for creating the app.

Prep quality was measured with the validated Boston Scoring Scale [9]. A score of 0, 1, 2, or 3 is given to the right, transverse, and left colon based on the amount and consistency of stool visualized as well as the ease or difficulty of guiding endoscopic instrumentation during a colonoscopy. Higher scores indicate a cleaner colon and a Boston score of 7 or above indicates an "excellent" prep. To eliminate bias, the 4 grading gastroenterologists in our study did not know whether subjects had used written or app instructions for their preps.

Patient arrival time at the hospital was taken from their electronic medical record as the time the patient signed in at the endoscopy suite. The number of telephone calls to the GI service from subjects was recorded.

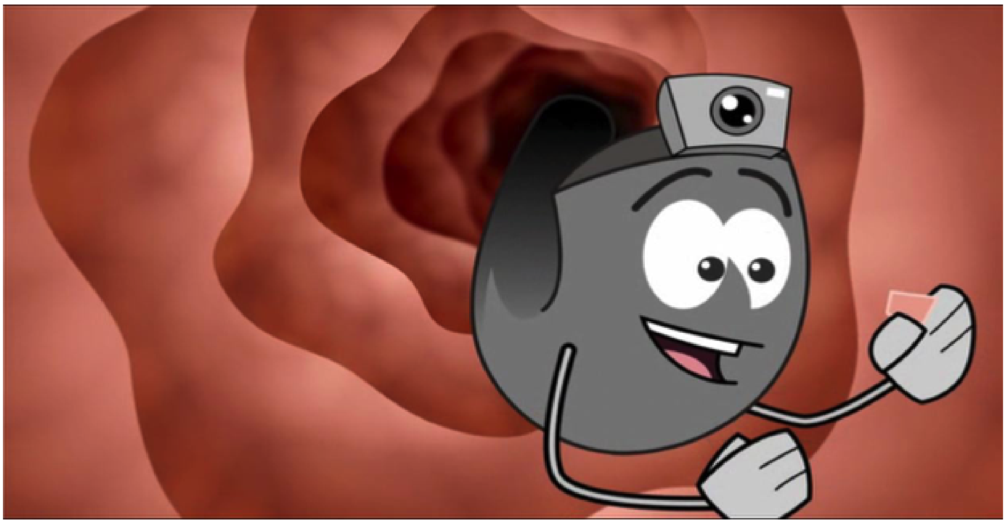
A written questionnaire was given to subjects' parents on the day of the colonoscopy using validated questions from in two previous studies on colonoscopy prep [10,11]. In the questionnaire, parents were asked to grade their knowledge about the procedure both before and after receiving either the app or written information. The patients were allowed to participate in the survey with their parents.

Of the 46 patients recruited, 23 were assigned to receive app instructions and 23 were assigned to receive traditional paper-based instructions. In total, 42 patients completed the study. Three subjects withdrew from the study. Two subjects forgot about their enrollment in the study and called our service for paper-based instructions. One subject who has been randomly assigned to receive app-based instructions became nervous about using the app and decided against using an experimental prep process. One control subject consented but was withdrawn after his prep was changed to another laxative formulation. Our final subject sample comprised 22 control and 20 experimental subjects.Statistical analysis was performed using IBM SPSS Statistics, version 24.0 (IBM Corporation).

The study was approved by the Stony Brook University Hospital Institutional Review Board (#1132702) on November 15, 2014. All study data were collected between July 15, 2015, and May 1, 2020.

Figure 1. The home screen of the *SB Colonoscopy Prep* app.

Figure 2. The animated colonoscope "Scopey" featured in the app's video.



Results

App users had a mean Boston Scoring Scale score of 7.2 (range 3-9) versus a mean score of 5.9 (range 3-9) for users with written instruction (*P*=.02) (Table 1). In the app group, 75% (15/20) of users' Boston scores were 7 or above and therefore labeled as "excellent" preps. In the control group, 41% (9/22) of written users' Boston scores were categorized as "excellent" with scores of 7 or above (Table 2). On average, app users arrived 46 minutes and control users arrived 44 minutes prior to their procedure, with no significant difference between the two groups (*P*=.56). Based on questionnaire results obtained from subjects, 50% (10/20) of app users had improved knowledge of the colonoscopy versus 36.4% (8/22) of control subjects (*P*=.37).

All 20 app users were able to download, install, and operate the software without technical difficulties. Based on their survey answers, all app users completed the prep within the recommended time whereas only 18 patients (81.8%) in the control group managed to do this (*P*=.45). In total, 6 phone calls were made to the GI service by controls versus 2 calls from app users (*P*=.27).

Table 1. Study results.

Variable	Control subjects (written, n=22)	Experimental subjects (app, n=20)	*P* value
Age range (years)	6-18	5-18	—[a]
Average Boston score	5.9	7.2	.02
Patient arrival time to endoscopy suite (minutes before procedure)	44	46	.56
Calls to gastroenterology service, n	2	6	.27
Subjects with improved knowledge after receiving materials, n (%)	9 (36)	10 (50)	.37

[a]Not applicable

Table 2. Boston scores for app and written instruction users.

Boston score	Subjects	
	Written (n=22), n (%)	App (n=20), n (%)
3	1 (5)	1 (5)
4	5 (23)	0 (0)
5	5 (23)	2 (10)
6	2 (9)	2 (10)
7	4 (18)	6 (30)
8	3 (14)	4 (20)
9	2 (9)	5 (25)

Discussion

Principal Findings

Subjects who used an app to guide them through their colonoscopy prep had better prepped colons compared with patients who used paper-based instructions for their prep. App users had higher Boston scores, indicating better preps, and a higher percentage of scores classified as “excellent cleanout” than patients who used written instructions. This is similar to studies in adults comparing colonoscopy prep quality in subjects using app versus paper-based instructions. In a study by Lorenzo-Zúñiga et al [5], 100% (N=108) of the subjects using an interactive app for colonoscopy prep had a successful bowel prep compared to 96.1% (146/152) of those in the control group receiving written instructions for their preps (*P*=.037). Kang et al [6] demonstrated the benefits of app-based instructions, with 82.2% (318/387) of preps deemed adequate in adult subjects who used an interactive app vs 69.5% (266/383) of preps deemed adequate in control subjects who received written instructions (*P*=.001).

While both groups in our study received the same instructions about colonoscopy prep, including medication names, dosages, and when to take each medication, the app had features that reduced the chances of missed or delayed medications. The app users had this information continually given to them throughout the prep process. For example, 4 hours after app users began to take the polyethylene glycol mixture, the app alerted them that it was time to take a 2-hour break. Two hours later, the app alerted users to begin the second half of the prep. Sixty minutes before the patient was supposed to finish their prep, the app alerted users that they had 1 hour left to finish taking their medications. There was a countdown clock visible to the user throughout the prep process, informing them how much time was left in each part of the prep process. Even when their smartphone display screens were off, the app caused the smartphone to sound an audible alarm or vibrate and flash information on the screen about the next step in the prep process.

Limitations

Patient knowledge, the number of phone calls to the GI clinic, and punctuality did not show statistical differences between the 2 study groups. This may be due to the small number of subjects in the study. Future studies with a larger sample size may be needed to increase study power to investigate if an interactive app could affect these variables.

The use of a mobile phone–based health aid does not always result in improved outcomes, and the availability of such apps does not mean patients will want to use them. A study by Ting et al [12] on 70 adolescents with systemic lupus erythematous failed to show improvement with their hydroxychloroquine adherence while using a mobile phone–based reminder system. Perski et al [13] demonstrated that nonmedical factors such as the color scheme, design, and user ratings influence whether users will choose to use an app [13]. There is still insufficient economic data supporting the use of mobile health apps. Many smartphone app studies to date have been pilot studies with limited data [14]. Reviews of these studies also suggest there may be a lack of data on the benefits of smartphone-based health apps in low-income communities [15].

Conclusions

This is the first study to demonstrate significant improvement in colonoscopy prep in pediatric patients with the use of a smartphone or tablet app in a typical clinical setting. Future studies will continue to investigate the benefits of mobile health software in the management of pediatric patients and their families.

Acknowledgments

The authors wish to thank Arlen Raisbeck for his contributions to this study.

Conflicts of Interest

DL is a cofounder of Lerner Media Inc. This company helps with multimedia production. No payment or royalties were collected for the creation of the Scopey video.

Multimedia Appendix 1
“Upper and Lower Colonoscopy” video by the Children’s Hospital of Wisconsin.
[MP4 File (MP4 Video), 23487 KB - pediatrics_v3i2e18174_app1.mp4]

Multimedia Appendix 2
CONSORT-eHEALTH Checklist (V1.6.2).
[PDF File (Adobe PDF File), 99 KB - pediatrics_v3i2e18174_app2.pdf]

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Abbreviations

GI: gastroenterology
NASPGHAN: North American Society for Pediatric Gastroenterology, Hepatology and Nutrition

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Viewpoint

Pediatric Mental and Behavioral Health in the Period of Quarantine and Social Distancing With COVID-19

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Abstract

The coronavirus disease (COVID-19) pandemic has spread rapidly throughout the world and has had a long-term impact. The pandemic has caused great harm to society and caused serious psychological trauma to many people. Children are a vulnerable group in this global public health emergency, as their nervous systems, endocrine systems, and hypothalamic-pituitary-adrenal axes are not well developed. Psychological crises often cause children to produce feelings of abandonment, despair, incapacity, and exhaustion, and even raise the risk of suicide. Children with mental illnesses are especially vulnerable during the quarantine and social distancing period. The inclusion of psychosocial support for children and their families are part of the health responses to disaster and disaster recovery. Based on the biopsychosocial model, some children may have catastrophic thoughts and be prone to experience despair, numbness, flashbacks, and other serious emotional and behavioral reactions. In severe cases, there may be symptoms of psychosis or posttraumatic stress disorder. Timely and appropriate protections are needed to prevent the occurrence of psychological and behavioral problems. The emerging digital applications and health services such as telehealth, social media, mobile health, and remote interactive online education are able to bridge the social distance and support mental and behavioral health for children. Based on the psychological development characteristics of children, this study also illustrates interventions on the psychological impact from the COVID-19 pandemic. Even though the world has been struggling to curb the influences of the pandemic, the quarantine and social distancing policies will have long-term impacts on children. Innovative digital solutions and informatics tools are needed more than ever to mitigate the negative consequences on children. Health care delivery and services should envision and implement innovative paradigms to meet broad well-being needs and child health as the quarantine and social distancing over a longer term becomes a new reality. Future research on children's mental and behavioral health should pay more attention to novel solutions that incorporate cutting edge interactive technologies and digital approaches, leveraging considerable advances in pervasive and ubiquitous computing, human-computer interaction, and health informatics among many others. Digital approaches, health technologies, and informatics are supposed to be designed and implemented to support public health surveillance and critical responses to children’s growth and development. For instance, human-computer interactions, augmented reality, and virtual reality could be incorporated to remote psychological supporting service for children’s health; mobile technologies could be used to monitor children’s mental and behavioral health while protecting their individual privacy; big data and artificial intelligence could be used to support decision making on whether children should go out for physical activities and whether schools should be reopened. Implications to clinical practices, psychological therapeutic practices, and future research directions to address current effort gaps are highlighted in this study.

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KEYWORDS

pediatrics; mental health; stay-at-home orders; health technology; digital interventions; social distancing; COVID-19

Introduction

Due to the spread of the coronavirus disease (COVID-19), people in many counties such as the United States, China, and Italy are restricted from leaving homes for anything other than essential activities [1-4]. The long-term home confinement has adverse effects on children's physical and mental health to a certain degree [5]. Studies have shown that children who experienced quarantine are more likely to report high depressive and stress symptoms [6,7]. Longer duration of home confinement may result in poor mental health and avoidance behaviors [5]. Since children are not engaged in their "normal" class schedules, they may be experiencing fewer physical activities, irregular sleep rhythm and unhealthy diets, and longer smartphone screen exposure, resulting in physical problems such as increased body mass and decreased cardiopulmonary fitness [8]. Children's mental and behavioral health are vulnerable to risks from the external environment, which will impact their development when they grow up [9]. Limited outdoor activities and lack of interaction with peers have a psychological impact on children as well. Lacking face-to-face contact with classmates and friends, and having a lack of personal space may also be detrimental to children's overall health [5,8]. These negative influences have been reported to be as risky as other traumatic experiences [10], so it is warranted to address children's mental and behavioral health.

Psychogenic and Stress Reduction

Stress response [11] refers to the human body's physical and mental response to an awareness of major changes or threats. Emotional states and clinical symptoms are influenced by the crisis, requiring psychological assistance and care. Anxiety and depression are common emotional reactions [12-14]. Specifically, preschool children may cry more and become clingy to others; school-aged children may be more nervous and scared, and repeatedly ask parents about the situation of the pandemic. Adolescents may have worries, irritability, and tantrums; some adolescents spend a lot of time watching the news about the pandemic [15]. Children of different ages may all experience poor appetite, insomnia, nightmares, etc [16,17].

Psychological and Behavioral Changes Caused by Stress Response

Mild stress or chronic stress response is manifested as mild emotional, cognitive, and physical symptoms, which has little effect on daily life [18]. Moderate stress response can last for a few hours, and it affects physical, emotional, and cognitive functions [19]. There may be increased alertness, mainly manifested as being easily frightened, accompanied by inattention, increased irritability, and anxiety. Even slight sounds can result in children's emotional instability and startled reactions. In this case, children need to seek professional psychological counseling for help. Severe stress [20] response seriously affects the life and learning abilities of children, which may lead to a series of psychotic manifestations [21]. If children have an emotional and behavioral stress reaction over 2 weeks, then they should go to the hospital for examination, diagnosis, and treatment, as well as psychiatric treatment as soon as possible to avoid prolonged illness [8].

Mild stress could increase attention, memory, and cognition in children, allowing them to adapt to changes in the external environment, which could be treated as a positive psychological response [22]. However, excessively intense stress can cause negative mental stress, such as dim consciousness; narrowed scope of consciousness; impaired attention; decreased memory, thinking, and imagination; and weakened learning ability [23]. Under stressful situations, children's attitudes toward outside could also be distorted. The narrowed scope of cognitive ability may cause children to just focus on pandemic situations, disease, and other related negative contents, and no longer care about other positive things in the surrounding environment. They are likely to pay more attention to negative consequences or bad news. Only with the recovery of the psychological disorder and ceasing to worry about the crisis can most children gradually return to a normal thinking mode and cognitive state [24].

Along with psychological stress response, the children's behaviors also seem to have changed [24]. This is the corresponding response that the body adopts to buffer the impact of stress and get rid of physical and mental tension, and adapt to the needs of the environment. Some children may have behavior inhibition reactions, such as a sense of loss and stupor, reduction of daily activities, unwillingness to communicate with others, and laziness in personal life [25]. They may also have anger, impatience, disobedience, and antagonism with families; experience interpersonal tension; and even behave with impulsive aggression [15].

For children who are infected, strict isolation in hospitals increases the distance between them and other people, which makes them feel helpless and desperate [26]. In these unfamiliar settings, children may not be able to control anxiety, cowardice, and stubbornness, thus showing resistance to treatment due to the environmental changes and fear of death. Some children with serious illness may even have symptoms such as a feeling of near-death, panic and despair, etc. Even when recovered, some children may continue to recall the details of the unpleasant experiences of being quarantined during the pandemic [27].

The Roles of Communities and Schools

Communities, neighborhoods, and schools need to be aware of this negative impact on children and take timely and effective actions to deal with these problems [28]. Online interactive courses that provide a better learning experience can promote children's healthy lifestyle while ensuring the content meets the educational needs without overburdening them. Communities or neighborhoods are usually important social resources to assist families and serve as a bridge between students and schools. Communities could invite psychologists to provide online services to cope with family conflicts, parent-child tensions, and mental health problems caused by concerns about the pandemic. Social workers in the neighborhoods play an active role in helping parents deal with family problems. This kind of social safety network is particularly useful for families in need or single-parent families.

Parents Are the Closest Providers for Children

The main cause of panic during the public health crisis is that it destroys the daily life [29] that people are familiar with; in other words, it destroys the sense of security. The state of mental health is not only a bridge and link between the body and mind but also an important factor closely related to child immunity. Children's stable emotions are the most powerful protection against viruses, so it is important to pay attention to children's emotions and to manage, counsel, and intervene symptomatically.

With the premise of safety, parents should try to maintain children's daily life rhythms such as work and rest balance and regular activities. Children should focus more on adequate daily activities such as reading, indoor sports, games, and handicrafts rather than paying too much attention to information about the pandemic. Entertainment activities can effectively relax their mind and brain. Parents should ensure that children have regular meals and nutrients, a comfortable family environment, and adequate sleep. Relieving psychological stress is the premise to ensuring a stable physiological state. Due to the COVID-19 pandemic, medical resources are limited to common mild diseases or chronic diseases. Meanwhile, going to health care settings may expose children to higher risks of getting infected. Point-of-care systems such as portable smart devices, [30] diagnosis technologies at home with the Internet of Things [31], and other digital interventions [32,33] play crucial roles to protect children during this period.

Families Are the Frontline Psychological Counselors for Children

Parents are the first and best teachers for children, and good educational style becomes particularly important during the period of the pandemic. In addition to monitoring children's performance and behavior, parents also need to respect children's sense of identity and needs, and help them improve self-management capabilities. During the public health emergency, adolescents who have a certain degree of education will be exposed to a large amount of information related to the pandemic [24]. Parents should actively communicate with adolescents with effective ways to help them relieve anxiety and avoid panic. A good parenting style can strengthen family bonds and satisfy children's psychological needs [34,35]. On the other hand, staying at home instead becomes a wonderful opportunity to strengthen parent-child relationships, facilitating children to actively participate in housework and improve abilities to take care of themselves.

During this special period, many parents are also prone to emotional instability and some of them even have quarrels and conflicts. These tensions and insecurity may be transmitted to the children with increased stress response [35]. Relieving stress helps children feel the safety and harmony of the family environment. Parents need to learn to perceive and adjust their emotions. For preschool children, when the child is crying and clings to others, parents could comfort them by touching and hugging, and could play games with them to relax and divert their attention; for school-age children and adolescents, parents need to listen patiently and accept their emotions when they are nervous. The attitudes of parental acceptance could help children restore calm. In contrast, if parents cannot listen patiently, but are eager to refute, reason, or even rebuke, this may only escalate the children's negative emotions.

Receiving scientific and objective information can reduce children's anxiety and promote their emotional stability. Many teenagers have access to relevant information but may be emotionally fluctuated by some misleading information on the internet. If they are too aggressive or indifferent, then parents should take actions to discuss and help them identify scientific and objective information by referring to official and authoritative sources. Paying more attention to the positive information in the news could increase the sense of hope.

The panic caused by the disease stems from the worst result it may cause; however, health care researchers and scientists from around the world have provided people with a large amount of scientifically feasible prevention knowledge and information [36,37]. Parents are supposed to work with children to develop disease prevention approaches based on their family's characteristics. Children should be encouraged to communicate with friends and families by phone or internet, which could increase their sense of connection with the same situation—an effective psychological protection against the feeling of isolation and helplessness.

The COVID-19 pandemic has become a new normal around the world [38]. Quarantine and social distancing are becoming regular features of people's daily life. Textbox 1 illustrates the negative influences of the long-term effects of physical and social isolation, and interventions for children.

Textbox 1. Impacts of the global public health emergency on children's mental and behavioral health and possible interventions.

Loneliness and relevant sequelae [39]

Using social media to bridge social distance [40,41]

Distress [42]

Open communication and discussions should be encouraged in case parents are underestimating children's concerns [12,42].

Anxiety, depression [43]

Tracking and reducing sustained feelings of loneliness [44]

Self-harm or suicide [45]

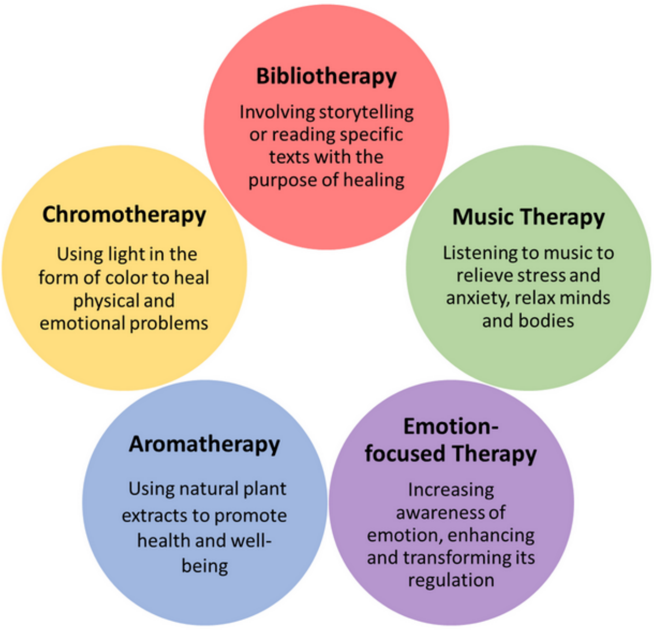
Promoting children's sense of belonging [46]

Implications to Clinical Practice

The emerging technologies have been playing an increasingly more crucial role during the COVID-19 pandemic [47]. Providers should take timely actions to ensure children's immediate health care needs are addressed, and children's families are supposed to be actively engaged. Since face-to-face care has become less accessible, remote consultation and diagnosis are more suitable. Telehealth has the capacity and is appropriate for pediatric specialists to provide services during the pandemic, but health care providers need clear evidence-based guidelines to support children's mental and behavioral health [48]. Children with mental illnesses are especially vulnerable during the quarantine and social distancing period. The inclusion of psychosocial support for children and their families are part of the health responses to disaster and disaster recovery. Pediatric clinical practices should reserve inpatient facilities for those children and adolescents for whom outpatient measures are not an adequate clinical option while using outpatient treatment options to the greatest extent possible. Adopting telehealth and telemedicine services enables the increased reliance on remote consultation and diagnosis, which further ramps up other necessary health care deliveries at children's homes.

Meanwhile, psychological therapeutic practices could be alternative intervention approaches for children's mental and behavioral health. Figure 1 demonstrates five common therapeutic approaches that could be applied to children with the guidance of health care providers and assistance from families.

Figure 1. Psychological therapeutic interventions and approaches.



Bibliotherapy involves storytelling and reading specific texts with the purpose of healing; through these cost-effective activities, children who have severe mental conditions could be adjusted to moderate or mild symptoms [49]. Chromotherapy leverages the color spectrum of light to balance energy on an emotional, physical, or spiritual level, thus aiding children with mental illnesses [50]. Children could also listen to music to promote wellness and manage stress, since this evidence-based intervention has been shown to improve emotional, cognitive, and communicative health and quality of life [51,52]. Additionally, with the guidance of health care professionals, parents may use aromatherapy to improve the physical health and spirits of children. Aromatherapy is a complementary treatment that uses essential oils medicinally to improve physical, psychological, or behavioral health [53]. Emotion-focused therapy (EFT) provides therapeutic approaches to connect parents and children, therefore improving problematic psychological states and interpersonal relationships. Meanwhile, EFT could consolidate the security gained through these new patterns of connection and restructure family's interactions [54].

Discussion

Families are the warmest havens for children. Parents are the closest supporters and protectors of children during the global pandemic. Maintaining close and open communication with children is the key to identifying their physical and mental health problems, and it provides corresponding actions and support. Psychological crisis interventions targeted to different psychological problems for different age groups should be conducted to reduce the psychological traumas and subsequent psychosocial problems caused by the pandemic. Communities and schools are playing unique and vital roles in supporting children by providing effective interventions with high efficacy. Parents and families should take more care of children's mental health in their early life pathways, as good educational strategies are particularly important during the COVID-19 pandemic.

Even though the world has been struggling to curb the influences of the pandemic, the quarantine and social distancing policies will have long-term impacts on children. Innovative digital solutions and informatics tools are needed more than ever to support the health care systems, thus mitigating the negative consequences on children. Diverse works have been introduced and mobilized around the world. For instance, interactive data visualization tools have been used to display the pandemic information [55], mobile health apps have been used to track symptoms and contact tracing [56], and data-driven models and advanced algorithms have been employed to predict pandemic situations, which helps different parties and departments to make responses [47].

Future research on mental and behavioral health of pediatrics should pay more attention to novel solutions that incorporate interdisciplinary interactive technologies and digital approaches; leveraging considerable advances in pervasive or ubiquitous computing, human-computer interaction, and health informatics among many others. Health care delivery and services should envision and implement innovative paradigms to meet broad well-being needs and children's health as the quarantine and social distancing over a longer term becomes a new reality [57]. Digital approaches, health technologies, and informatics are supposed to be designed and implemented to support public health surveillance and critical responses to children's growth and development. For instance, human-computer interactions, augmented reality, and virtual reality could be incorporated to remote psychological supporting services for children's health; mobile technologies could be used to monitor children's mental and behavioral health while protecting their individual privacy; big data and artificial intelligence could be used to support decision-making on whether children should go out for physical activities and whether schools should be reopened.

Conclusions

The physical and mental health of pediatrics directly affect their growth. Paying attention to the children and adolescents during the global public health emergency is of special social significance and clinical value for preventing the occurrence of mental disorders and adverse events. Humanistic care and psychological interventions for children should be included in the response strategies for the COVID-19 pandemic. The emerging digital applications and health services such as telehealth, social media, mobile health, and remote interactive online education are able to bridge the social distance and support mental and behavioral health for child populations. Health care delivery and services should envision and implement innovative paradigms to meet broad well-being needs and children's health as the quarantine and social distancing over a longer term become a new reality. Digital approaches, health technologies, and informatics should be designed and implemented to support public health surveillance and critical responses to children's growth and future development.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
EFT: emotion-focused therapy

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Viewpoint

Management and Treatment of Concussions via Tele-Concussion in a Pediatric Setting: Methodological Approach and Descriptive Analysis

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Abstract

Background: Approximately 2 million children in the United States sustain a concussion annually, resulting in an economic impact as high as US $20 billion. Patients who receive treatment at concussion specialty clinics, versus primary care, experience faster recovery, thereby reducing patient burden and subsequent medical-related costs. Accessibility to specialty clinics is typically limited by the availability of in-office visits. This is particularly relevant in light of the severe acute respiratory syndrome coronavirus 2 pandemic and subsequent guidance to eliminate all non–medically necessary in-clinic visits. Telehealth has been used to effectively deliver in-clinic care across several disciplines including psychiatry, psychology, and neuropsychology. However, a model of telehealth delivered concussion assessment, treatment, and management has not been established.

Objective: The purposes of this paper are to describe a pediatric concussion specialty clinic's experiences in delivering telehealth concussion services and to provide preliminary descriptive data on a sample of pediatric telehealth patients with concussions.

Methods: The specialty pediatric concussion clinic described here began providing telehealth services in 2019 and is part of the largest and fastest-growing telehealth hospital network in the United States. The clinical care process will be described, including accessing the telehealth platform, assessment during the initial appointment, injury management including communication with relevant patient stakeholders (eg, parent or guardians, athletic trainers), dissemination of rehabilitation exercises, and nature of follow-up visits. Descriptive data will include patient demographics, the radius of care, the time between the date of injury and initial visit, the average number of follow-up visits, and days until medically cleared for return-to-learn and return-to-play.

Results: The analytic sample included 18 patients with concussions who were seen for all of their visits via telehealth between August 2019 and April 2020. The mean age of the sample was 14.5 (SD 2.5) years. The radius of care was a median of 17 (IQR 11.0-31.0) miles from the clinic with a median time between injury and the first visit of 21 (IQR 6.0-41.5) days. The mean number of visits was 2.2 (SD 0.8) with a median days between visits of 5.4 (IQR 3.0-9.3) to manage and treat the concussion. Of the 18 patients, 55.6% (n=10) were medically cleared for return-to-learn or -play in a median of 15.5 (IQR 11.0-29.0) days.

Conclusions: Limited access to health care is a well-understood barrier for receiving quality care. Subsequently, there are increasing demands for flexibility in delivering concussion services remotely and in-clinic. This is the first paper to provide a clinically relevant framework for the assessment, management, and treatment of acute concussion via telehealth in a pediatric population.

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KEYWORDS

brain concussion; athletic injuries; sports injuries; telemedicine; eHealth; mHealth; telehealth; mobile health; adolescent; child; COVID-19

Introduction

Background

Sport-related concussions (SRCs) are a significant public health concern in the United States [1]. The prevalence rate of SRCs among US children (<18 years) is approximately 1400-2400 per 100,000 children, amounting to 1.9 million annual cases [2]. Pediatric SRCs increase the risk of short-term health problems including neurobehavioral changes (eg, fatigue, nervousness or irritability), cognitive impairment (eg, slowed reaction times, difficulty in concentrating), sleep disturbances, somatic symptoms (eg, nausea, vomiting, dizziness), or emotional symptoms [3]. Long-term problems include psychosocial outcomes (eg, hyperactivity, inattention) [4] during later childhood years and psychiatric disorders and premature mortality in adulthood [5]. These poor health outcomes related to concussions lead to a staggering economic impact on society [6]. There is evidence, however, that early diagnosis and treatment decrease symptom severity and reduce recovery time, diminishing the risk of short- and possibly long-term health outcomes [4,7].

Current Status

Recent advancements in the understanding of concussion management have resulted in better outcomes for patients. Beginning in 2001 the Concussion in Sport Group began releasing international consensus statements with recommended guidelines for the identification and management of concussions [8]. Over the past four consensus statements, return-to-learn (RTL) and return-to-play (RTP) guidelines have become more prescriptive and step-wise. RTL currently includes systematic progression from minimum academic activity with accommodations to a gradual increase in performing all academic activities equivalent to before injury [9]. RTP currently includes systematic progression from minimum physical activity to eventual full-return of sport-specific activity, including full-contact practice [9]. This step-wise progression for RTP has resulted in an increase in average days of recovery in high school and collegiate athletes, as well as a significant reduction in the number of repeated concussions and duration between multiple concussions [10]. Additionally, international and national consensus statements advocate for targeted referrals to specialty clinics (eg, physical, vestibular, or cervical therapy). These specialty clinics then hold the responsibility to determine RTP and RTL [10-12]. Accordingly, there has been an increase in referrals to specialty multidisciplinary concussion clinics based on the evolution of concussion consensus statements and guidelines [13].

Challenges

Despite an increased need for specialty concussion clinics, access is limited. It is well documented [14] that the physical distance between patients and clinics limits patient accessibility. This assumes the patient has access to a reliable mode of personal or public transportation. Given that concussion specialty clinics are relatively rare in the United States and typically only located in major metropolitan areas [15,16], access for the majority of US residents including those residing in rural areas is particularly limited. The scarcity of specialty concussion clinics further limits the availability of appointments and makes it difficult to receive appropriate care in the acute phase of injury [17,18]. This is important because early symptom burden is often the strongest predictor of recovery [19], with targeted interventions being more effective than rest and graded-exertion alone [20].

A possible mechanism to overcome the issue of accessibility is remotely delivered care or telehealth. Telehealth platforms have been used to effectively deliver in-clinic care across several disciplines including primary care, neurology, behavioral health, psychiatry, and neuropsychology [21-25]. Research shows no difference in patient ratings of therapeutic alliance and treatment satisfaction of in-clinic visits versus telehealth platforms, including concussion care and management delivered through telehealth (tele-concussion) specifically [26]. Despite some preliminary evidence on the efficacy of tele-concussion, few providers offer these services. However, the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) outbreak in March 2020 forced many providers to offer telehealth services to slow transmission by limiting person-to-person exposures [27]. This recent rise in tele-services and general overall client satisfaction will likely lend itself to a further increase in use of telemedicine [28].

Solutions

However, best practices for telehealth delivery for the assessment, treatment, and management of concussions have not been established. The primary purpose of this paper is to describe the methodological approaches of one pediatric concussion clinic's transition to tele-concussion. We will also provide preliminary descriptive data on a sample of pediatric telehealth patients with concussions. Providing an example of how one clinic implements tele-concussion services can spur other providers to work through concerns and implementation logistics. In addition, preliminary descriptive data can help the field in discerning what are important variables to consider in future empirical validation studies on tele-concussion.

Methods of Service Delivery

Children's Health Andrews Institute

Children's Health Andrews Institute (CHAI) is a pediatric sports medicine and orthopedic clinic located in the Dallas/Fort Worth metropolitan area. Within CHAI, there are several specialty clinics including a concussion clinic. This multidisciplinary concussion clinic saw over 600 new pediatric concussions in 2019 with a portion of those seen via telehealth for follow-up visits only. Following the SARS-CoV-2 outbreak, CHAI began a transition to an all telehealth setting for all patient visits in March 2020. To have an understanding of the clinic's methodological approach to tele-concussion, we will provide a brief overview of the in-person approach.

In-Person Clinic Methods

Consistent with consensus guidelines [9], once a patient is suspected of sustaining a concussion, they are evaluated in-clinic and provided targeted recommendations for RTL and RTP. This initial evaluation includes a brief clinical interview along with symptom, vestibular, ocular motor, and cognitive screening. Once concussion diagnosis is confirmed, the patient is given paperwork outlining individualized RTL and RTP progressions that the patient disseminates to necessary school personnel. Outside specialty referrals are made as necessary (eg, physical therapy, vestibular therapy) and follow-up visits scheduled.

During the follow-up visit, progress and recovery are re-evaluated through a brief clinical interview; symptom screening; and vestibular, ocular motor, and cognitive functioning screening. This aggregate data informs modifications to recovery protocols for RTL and RTP. If recovery is not progressing or symptoms are worsening, a referral is made (eg, physical therapy). Depending on progression of RTL and RTP protocols, patients may require additional follow-up visits.

At a patient's clearance and final visit, the treating provider determines if the patient has successfully completed RTL and RTP protocols. During the final visit, a clinical interview; symptom endorsement; and vestibular, ocular motor, and cognitive functioning screening are conducted to determine if the patient has returned to their baseline levels. Once cleared by treatment provider, the patient is provided a medical clearance note for school and sports. Although the total number of visits vary, the average is 2-3 visits spanning over several weeks.

Tele-Concussion Clinic Methods

The first step in transitioning an in-clinic concussion management program to a telehealth delivered program is to establish a video delivery platform accessible to patient and provider. There are various telehealth platforms that can serve as this communication tool. It is important to discuss with your organization which platforms are compliant with their institutional policies and standards such as the Health Insurance Portability and Accountability Act (HIPPA). The CHAI concussion clinic uses an internal entity, which patients can access via a website or mobile app (requires downloading to a mobile device), though other HIPPA compliant telehealth videoconferencing platforms can be used.

The second step that should be considered in transitioning an in-clinic concussion management program to a telehealth delivered program is to convert all patient materials that are typically delivered or provided to the patient in hard copies into digital copies. At CHAI, this includes a patient handout describing what a concussion is and general tips to help maximize recovery. These materials are delivered to patients at CHAI through an internal patient portal, but they could also be delivered via email or other patient portals if available through a hospital network.

The third step in this transition is to convert all testing delivered to the patient in-clinic to a virtual delivery. In the CHAI concussion clinic, this included the Post-Concussive Symptom Checklist (PCSS) [29], the Vestibular Ocular Motor Screener (VOMS) [30], and computerized neurocognitive testing. The PCSS is a self-reported symptom checklist that was converted to a digital form that can be delivered to the patient via email or patient portal. If administered on a digital platform (eg, RedCap, My Patient Portal), the patient can receive, complete, and return the form online. Otherwise, the patient may have to print the document, complete it, and scan or return it to the provider. In the CHAI concussion clinic, patients fill out the PCSS online via patient portal at the beginning of their virtual visit. For the VOMS, there are several steps necessary to administer this screening tool virtually. First, patients are informed prior to their visit that the following materials are needed: a ruler with centimeters, a pencil, and a metronome (this can be through a mobile phone app or online). Prior to administration of the VOMS, patients are instructed to have their cameras positioned so the clinician can see their eye movements during the screening. Second, similar to in-person administration, a baseline for symptoms (Likert-scale 0-10) of headache, dizziness, nausea, and fatigue are collected. After a baseline of symptoms are collected, in-person administration of the VOMS requires the clinician to provide the stimulus to guide the patient in performing the vestibular and ocular movements of the screening while noting if any of these movement patterns provoke symptoms (an increase from baseline symptoms collected). For telehealth, the clinician is still guiding the patient through movements, but they are now directing the patient on how they can do these movements on their own. This requires the clinician to first demonstrate how to use a pencil to perform the movements of the ocular screening portion of the VOMS: smooth pursuits, vertical and horizontal saccades, and convergence with the additional use of a ruler in centimeters. Each portion of the ocular motor screening is demonstrated by the clinician and then practiced by the patient to ensure accuracy. Once the patient is able to perform a specific portion of the ocular screening, such as smooth pursuits, the patient then rerates symptoms of headache, dizziness, nausea, and fatigue to note if that movement pattern resulted in symptom provocation. The clinician then demonstrates with pencil and metronome how the patient is to perform movements of the vestibular screening of the VOMS: horizontal and vertical vestibular-ocular reflex, and visual motion sensitivity test. Similar to the ocular motor section of the VOMS, each portion of the vestibular screening is demonstrated by the clinician and then practiced by the patient to ensure accuracy. Once the patient is able to perform a specific portion of the vestibular screening, such as vestibular-ocular reflex, the patient then rerates symptoms of headache, dizziness, nausea, and fatigue to note if that movement pattern resulted in symptom provocation. For computerized neurocognitive testing, similar to in-person visits, supervision of testing is provided during telehealth visits.

The fourth step in this process is to prepare any other materials for a postclinic visit that may be needed to supplement care. Similar to in-person visits, individualized paperwork outlining RTL and RTP are provided to the patient but through the patient portal. This paperwork is then disseminated to necessary school personnel by the patient.

Finally, the actual patient visit requires some steps to successfully transition an in-clinic concussion management program to a telehealth delivered program. Although patient clinical care in the tele-concussion clinic is similar to the in-person clinic, an important difference is the previsit preparation. Before the initial visit or assessment the patient's parents or guardians are emailed instructions on how to access the virtual health platform. Patients are instructed to log into the telehealth app prior (approximately 15 minutes) to all appointments to troubleshoot any technical difficulties that may arise. A member of the concussion clinical team is made available to the patient via telehealth, if necessary, to assist with any problems connecting. All other elements of the tele-concussion visits remain the same as the in-person (referrals to specialty clinics, etc).

Preliminary Data

A secondary objective of this paper is to provide preliminary descriptive data on a sample of pediatric telehealth patients with concussions. Descriptive statistics on patient demographics (age, sex, race or ethnicity, and patient location), patient visits (time to first visit, total number of visits, time between visits), and patient recovery (recovery time, medical clearance) were evaluated for missingness and normality, and reported appropriately as proportions, means, medians, and ranges.

All data were collected from a deidentified clinical database and received exempt status from the Children's Health Institutional Review Board.

Evaluation Outcomes

Participants' (N=18) age ranged from 9-20 years, with a mean of 14.5 (SD 2.5) years. The majority of patients (n=14, 77.8%) were female, non-Hispanic White (n=14, 77.8%), located in-state (n=17, 94.4%), and medically cleared for RTP or RTL (n=10, 56.6%). Participants were located in a median of 17 (IQR 11.0-31.0) miles from the CHAI and required a mean of 2.2 (SD 0.8) visits. There was a median of 5.4 (IQR 3.0-9.3) days between visits, and patients took a median of 15.5 (IQR 11.0-29.0) days to recover fully (see Table 1 for more details).

Table 1. Descriptive statistics on patients using a pediatric tele-concussion clinic, 2019-2020 (N=18).

Characteristic	Value
Age (years), mean (SD)	14.5 (2.5)
Sex, n (%)	
Male	4 (22.2)
Female	14 (77.8)
Race/ethnicity, n (%)	
Non-Hispanic White	14 (77.8)
Hispanic	3 (16.7)
Non-Hispanic Black	1 (5.6)
Patient location	
In state, n (%)	17 (94.4)
Distance from clinic (miles), median (IQR)	17 (11.0-31.0)
Distance from clinic (miles), range	2-863
Patient visits	
Time to first visit (days), median (IQR)	21 (6.0-41.5)
Time between visits (days), median (IQR)	5.4 (3.0-9.3)
Total number of visits, mean (SD)	2.2 (0.8)
Total number of visits, range	1-4
Patient recovery	
Recovery time (days), median (IQR)	15.5 (11.0-29.0)
Medically cleared, n (%)	10 (55.6)

Discussion

Telehealth for Concussion Care

In the wake of the SARS-CoV-2 outbreak, general medicine and specialty clinics are rapidly adapting delivery of clinical care. Consistent with the primary objective of this paper, the methodology of converting a specialty clinic's in-person visit to a telehealth visit were described. Telehealth for concussion care was initially implemented at this clinic starting in 2019. This previous experience in telehealth delivery allowed for an easier transition to all telehealth visits when mandated by the hospital system on March 17, 2020, in response to the SARS-CoV-2 outbreak.

Potential Challenges of Telemedicine

This study demonstrates how to administer tele-concussion services effectively. However, this does not come without challenges. First, adapting administration of measures such as VOMS to telehealth took time and practice. At CHAI concussion clinic, providers practiced telehealth administration multiple times with one another to ensure familiarity and to troubleshoot administrative difficulties. Clinics will have to consider similar preliminary exercises for any measures delivered via telehealth.

Second, technical issues were unavoidable. Internet bandwidth and Wi-Fi quality varies for patients and can result in connectivity issues. In our experiences, having the patient log-in to their visit prior to the appointment provides opportunities for troubleshooting including log-in assistance. This also provides opportunities to remind patients to minimize distractions, use a larger screen (ie, computer or tablet), and maximize internet speed (ie, have others log-off shared Wi-Fi, using a phone's Wi-Fi hotspot for the device used for the visit). Other technical difficulties will inevitably arise and keeping a log of issues with resolutions as a quick reference will prove valuable. Additionally, providing the patient with a one-page document, in simple language, with visual instructions on how to access the telehealth platform and information on materials needed for the visit, such as items to assist with VOMS administration, is useful. Some telehealth platforms, including the one used in this study, may automatically disseminate this information. Although most technical difficulties can be resolved through troubleshooting, there are times a visit will simply have to be rescheduled.

Finally, outside referrals may need to be made in areas beyond your typical referral network radius, requiring a widening of known specialty providers such as physical or vestibular therapy. In rare instances, an outside referral may require the patient to travel. It is important to highlight that patients from rural areas are often accustomed to occasionally traveling longer distances for specialty care.

Future Research

The results presented herein found the average recovery time was within the expected 28-day window [19], and the number of average visits was consistent with the number of in-person clinic visits. These preliminary data demonstrate the potential utility of tele-concussion services; however, future research is needed to expand upon and validate these findings. Future studies should also include examining potential differences in access to clinic and average recovery time of tele-concussion versus in-person clinic treatment. The measures delivered via telehealth should also be validated before being widely disseminated.

Conclusions

The recent SARS-CoV-2 pandemic created unprecedented alterations to the delivery of medical care. As such, there has been an increase in specialty clinic providers transitioning treatment platforms to telemedicine. Despite the unfortunate circumstances, patient accessibility to specialty concussion clinics will increase, thus providing the opportunity for a reduction in health care costs associated with concussion management [31]. This paper highlights how one clinic transitioned to tele-concussion delivery, providing considerations for how others might embark on a similar transition. Though initial adaption to technology will present challenges, this paper presented some suggestions to facilitate the transition to telehealth. Preliminary data shows promise that the average number of visits and average recovery time are comparable to in-person clinic treatment, with future research needed to confirm these findings. To our knowledge, this is the first paper to provide a clinically relevant framework for the assessment, management, and treatment of acute concussion via telehealth in a pediatric population.

Authors' Contributions

TC II and GPK had full access to all of the data in the study and take responsibility for the integrity and accuracy of the data analysis. TC II, JA, and SOB were responsible for the conceptualization and design of the study. TC II and GPK were responsible for the acquisition, statistical analysis, and interpretation of the data. All authors were responsible for the drafting and critical revision for intellectual content of the manuscript. SOB was responsible for the supervision of the study.

Conflicts of Interest

None declared.

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Abbreviations

CHAI: Children's Health Andrews Institute
HIPPA: Health Insurance Portability and Accountability Act
PCSS: Post-Concussive Symptom Checklist
RTL: return-to-learn
RTP: return-to-play
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
SRC: sport-related concussions
VOMS: Vestibular Ocular Motor Screener

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Viewpoint

Patient and Clinician Perspectives on Adolescent Opioid Use Disorder Treatment During a Pandemic: One Step Back, but Two Forward?

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Abstract

Opioid use disorder (OUD) is one of the most pressing public health problems in the United States and is highly prevalent among adolescents and young adults (AYAs). However, only a small percentage of AYAs with OUD ever receive treatment. Further, among those that do receive treatment, a substantial proportion of patients continue to struggle with OUD, and many prematurely drop out of treatment. These challenges have only been heightened in the face of the COVID-19 pandemic, but greater utilization of telehealth and mobile technologies by OUD patients may help counter these barriers, which ultimately may improve AYA OUD treatment in the postpandemic period. This viewpoint presents the perspective of a person in OUD recovery using online and mobile technology to support his own OUD recovery combined with thoughts from two clinicians supporting AYAs with OUD. Their perspectives may provide insights to help counter COVID-19–related consequences and offer clues to improving AYA OUD treatment in the long term.

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KEYWORDS

adolescent; opioid use disorder; treatment; telehealth; drug; perspective; opioid; COVID-19; young adult

Introduction

Over the last decade, opioid use disorder (OUD) has been among the most pressing public health problems for adolescents and young adults (AYAs) in the United States [1,2]. Now, matters have become even more challenging in the context of the COVID-19 pandemic. Treatment is more difficult to access, widening the already large treatment gap for AYAs with OUD [3]. Fatal overdoses appear to be on the rise likely as a result of social isolation (fewer bystanders available to administer overdose reversal medication) [4]. Furthermore, there is increased risk of severe COVID-19 illness among AYAs with OUD because many are immunocompromised due to smoking, chronic hepatitis, and HIV [5].

Recent changes in the OUD treatment landscape may help counter the negative impact of COVID-19, including federal policy changes decreasing restrictions on buprenorphine prescribing [6] and increased availability of online OUD recovery services. In understanding the implications of these policy-level changes, it is important to garner the perspective of stakeholders on the “ground level,” including clinicians providing OUD treatment and individuals in recovery.

We focus our viewpoint piece on the implications of changes in treatment from in-person to online clinical care, telehealth, and peer support, as well as specific aspects of entering versus maintaining OUD recovery.

Patient Perspective

My journey on the OUD recovery path, beginning as a young adult, has been built upon frequent contact with in-person social supports. I've had the privilege of supportive parents and a sober recovery environment that many AYAs with OUD do not have. I also recognize, however, that I have been consistently one of the youngest members of nearly all the mutual-support recovery meetings I have attended. This reality was only heightened when I re-enrolled in college in a small rural Ohio town, with only a few available meetings and the average age of meeting attendees was nearly 50 years old. Today, during the COVID-19 pandemic, the in-person meetings are certainly missed, but the opportunity to connect with young adults is no longer limited by geography. A plethora of online mutual support recovery meetings exist (worldwide) online. This may not only aid AYAs who are in small numbers at most mutual support recovery meetings, but also any other subpopulation that might be underrepresented.

Of course, there are likely unique benefits to in-person meetings that might otherwise be suboptimal online. For example, accountability to other members in recovery may become less salient or harder to maintain. Recently, an AYA shared in a mutual support meeting that he had gone "cold turkey" and had not "used" for 13 days. He was passing his time walking up and down his block compulsively to distract himself from his cravings and general angst. He stated he would return to join the group again next week…he did not show. Perhaps online meetings lacked the accountability he needed, and in-person meetings would have been better. Alternatively, maybe he would have never attended in-person meetings, and the online format was his first step toward recovery. It is hard to know. For online mutual support, the barriers to recovery support may be lowered, but maintaining recovery may be more challenging in some respects, particularly in terms of accountability.

The timing of OUD recovery, whether initiating or maintaining recovery, may be critical for the usefulness of online versus in-person supports. Early OUD treatment and recovery is complex as one navigates postinpatient treatment and transition to outpatient OUD medications. After inpatient treatment, my transition to outpatient care was complicated by various medication side effects and withdrawal symptoms, requiring frequent communication with my physician. I now realize this was a critical moment in my recovery, where any misstep could have had serious consequences. Initiation and management of OUD medication in the early phases of recovery during COVID-19 may be particularly tricky to navigate. Medication modifications may be needed, providers may not be able to give timely support, and patients may run out of their prescription if they have contracted COVID-19. Now, I also recognize that if online supports were specifically made available for family members supporting those in recovery, it may lower the barriers for them to receive support as well.

Maintaining OUD recovery during COVID-19 has presented me a unique set of challenges. One of the most salient has been the transition from in-person to online recovery support meetings. Social connections with people in OUD recovery have been a mainstay of my own recovery. Online communities have changed the quality of my social interactions in ways that are both helpful and unhelpful. I often feel more comfortable being vulnerable online, partly because the pixelated live stream of my webcam provides a cloak of anonymity. However, social exchanges feel less poignant, lacking a degree of joy, collective empathy, and physical contact. Another ongoing support for recovery I've explored is the use of mobile health addiction apps, which offer features ranging from mutual support "meeting locators" to coping and psychological well-being exercises. The potential usefulness of these apps seems particularly important given the lack of in-person resources during the COVID-19 pandemic. However, despite a large increase in the prevalence of these apps over the past few years, I have yet to find one that is consistently useful and engaging. But I am holding out hope that I will find an app that I will use consistently, as some apps are already showing efficacy [7]. Overall, I am hopeful that both online social supports and mobile apps can increase access and support for AYAs in addiction recovery.

Clinician Perspective

Our experience of collectively providing almost two decades of office-based opioid treatment (OBOT) to AYAs with OUD has been challenged with the onset of the COVID-19 pandemic. Under normal circumstances, initiation of OBOT in an AYA requires a comprehensive in-person evaluation including urine drug screening. However, in light of the extraordinary circumstances presented by the COVID‐19 public health emergency, providers should feel free to prescribe buprenorphine to new patients with OUD following an evaluation via telephone-based voice calls without first performing an in‐person or telemedicine evaluation [6].

Since the onset of Ohio's shelter-in-place order, our clinic has seen some increase in the number of AYA seeking OBOT services, although our numbers are small. In the 3 months after the shelter-in-place order (April-June), 5 AYAs presented for treatment compared to 2 patients in the 3 months prior (January-March) (historically, we saw no difference in new patient intakes between quarter 1 to quarter 2 during the years 2017-2019). Traditionally, our practice is to perform an in-person initial evaluation with our multidisciplinary team, as well as provide education on medication use, risk of relapse and overdose, and proper use of overdose reversal medications for the patient and support person. A full medical evaluation, including a complete physical examination, serology testing for hepatitis, screening for sexually transmitted infections and HIV are also performed. Although we offered telephone- and video telehealth–based initial evaluations for AYA entering treatment (with the changing insurance landscape, only video telehealth is now available), we have continued to recommend in-person visits, feeling that the benefits outweigh potential risks for most. We have had concerns that the collective social support of the treatment team would be less palpable in a telehealth setting and less likely to alleviate distrust one might have based on previous negative medical interactions. Precautions put in place in the clinical setting to minimize risk include universal masking of patients/visitors, limit of one support person for AYAs <18 years, decreased overall clinic in-person volume, general disinfection/hygiene procedures, and appropriate personal protective equipment for patients and providers based on institutional protocol. To date, encouragement of in-person visits for treatment initiation and the early phases of recovery has not appeared to impact care. Patient engagement with services seems similar to the previous year, with 80% of new patients returning for a follow-up visit post pandemic as compared to 75% in the year prior. However, it is worth considering whether we would have achieved a 100% follow-up rate had we been equally as supportive of telehealth and in-person follow-up for those in the early stages of recovery.

For patients maintaining recovery, we worked to transition them initially to telephone- and now to video telehealth–based care. Although there is concern of potential impact on the lack of urine drug screening accountability, given the safety profile of buprenorphine, the benefits of providing extended prescriptions and refills via telehealth are greater than the risk of severe adverse events like fatal overdoses [8]. To date, all our patients in early remission or sustained recovery (N=35) have remained engaged in treatment, and none have been lost to follow-up. Many patients have found safe, confidential spaces to have their telehealth visits and feel this continues to aid them in their recovery. One patient who struggled to connect during in-person visits, as she needed to bring her children to all appointments, has now been able to engage in lengthy telehealth sessions. However, some still request in-person treatment as the best option for ongoing care, stating that the human connection and increased accountability are beneficial. Furthermore, patients undergoing relapse or those who do not have reliable access to a telephone or video device may also benefit from being seen in person. Patients have been advised to notify us if they are under quarantine to ensure continued access to their medications.

Overall, our initial experience suggests that telehealth is a viable alternative to OBOT for AYA with OUD. Clinic metrics such as return for follow-up visits do not appear to have been negatively impacted. We have been somewhat reluctant to fully embrace telehealth for new patient visits; however, our assumptions on this could be wrong. It is worth exploring whether telehealth treatment initiation increases access without losing any of the benefits of in-person treatment support for those early in recovery.

Conclusion

Support and management of OUD recovery have been complicated with the arrival of COVID-19. Recent changes in the treatment landscape, including growing telehealth options and decreased restrictions on medication provision, have been directly in response to these current challenges. Although unique considerations may be needed for those entering versus maintaining OUD recovery, from a patient and provider perspective, these changes increase access to care, are helpful elements in the OUD treatment toolbox, and should remain an integral part of treatment after the pandemic.

Authors' Contributions

SWS, ERM, and AEB conceptualized the manuscript, wrote the initial draft, and reviewed and revised the final manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

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Abbreviations

AYA: adolescent and young adult
OBOT: office-based opioid treatment
OUD: opioid use disorder

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Viewpoint

Psychosocial Challenges and Opportunities for Youth With Chronic Health Conditions During the COVID-19 Pandemic

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Abstract

School closures, altered access to health services, and economic stress during the COVID-19 pandemic have likely had an impact on the mental and physical well-being of youth worldwide, particularly among those with chronic health conditions (CHCs). A number of challenges and opportunities have emerged during the COVID-19 pandemic for youth with CHCs. Challenges include heightened anxiety, disrupted routines, academic and social stresses associated with school closure, increased risk of domestic violence and abuse, and reduced access to physical and psychosocial support. On the other hand, opportunities include reduced academic and social stress, increased time with families, reduced access to substances, easier access to health care using technology, and opportunities to build resilience. This viewpoint paper highlights both challenges and opportunities for youth with CHCs during the pandemic and offers recommendations for further research and clinical care.

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KEYWORDS

COVID-19; coronavirus; pandemic; chronic illness; youth; adolescents; children; psychosocial; anxiety

Introduction

The COVID-19 pandemic has disrupted the daily routines and peer interactions of millions of youth worldwide via mandated social distancing, rapid and sometimes repeated lockdowns, and prolonged school closures. Although little has been formally reported and the full impact of these measures may not be apparent for some time, it is likely that those with chronic health conditions (CHCs) who already face a disproportionate psychosocial burden will experience additional consequences [1]. Some of these consequences are likely similar to the general population and others will relate to their existing health issues. As not all effects of the pandemic are likely to be detrimental, we outline both the potential challenges and opportunities for youth with CHCs as well as recommendations for further research and clinical care.

Psychosocial Challenges

Some of the key challenges likely to be faced by children and young people with CHCs during the COVID-19 pandemic include heightened anxiety regarding health and well-being; stress of disrupted routines; academic and social challenges associated with school closures; increased risk of family stress, domestic violence, and abuse; and reduced access to physical and psychosocial support. We discuss these challenges in this section in detail, and a summary of the challenges and strategies to address them is included in Textbox 1.

Textbox 1. Psychosocial challenges and strategies for children with chronic health conditions during COVID-19.

Heightened health anxiety

Encourage developmentally appropriate communication with children about emotions and concerns

Disrupted routines

Establish predictable new routines

School closures

Encourage social/peer connection via technology

Family stress/risk of domestic violence

Prioritize monitoring and support of at-risk families and ensure the availability of safe houses for victims of domestic violence

Reduced physical and psychosocial support

Encourage families to use tele-health/digital therapies offered by health care providers

Heightened Anxiety Regarding Health and Well-Being

For multiple reasons, including the demands of ill health, treatment, and readjustment to usual life following periods of medical treatment, children and young people with CHCs are at greater risk of developing psychological problems, especially anxiety [2]. Currently, services for these patients are limited, as are face-to-face and eHealth interventions, particularly those targeted toward health anxiety [3,4]. Partly due to the real dangers associated with the virus, the rapidity of lockdown, and the immediacy of social media, the COVID-19 pandemic has resulted in significantly increased rates of anxiety in the general population. Among those with life-threatening illnesses such as cancer, worries about social isolation, catastrophization about personal health, and guilt about family support have been even greater [5-7]. Studies of children from China have also identified clinginess, distraction, irritability, and fear of asking questions about the pandemic, more so in those who reside in highly affected regions [8]. It is not just those with physical health issues who are vulnerable. A recent UK survey of over 2000 young people with a history of mental health problems found that 51% of participants believed that their mental health had deteriorated due to the pandemic, and many reported increased psychological distress and loneliness [9]. Fortunately, there is emerging evidence suggesting that effective communication and distraction can help to protect children's psychological health [8,10].

Stress of Disrupted Routines

There is some evidence that children with attention-deficit/hyperactivity disorder (ADHD) and autism spectrum disorder (ASD), who usually thrive with predictability and routine, have been more affected by the disruption to routines during the pandemic than other groups. Children with ADHD have been found to display a greater level of symptoms that are related to family stress and can be reduced by establishing predictable new routines [11]. Those with ASD have also been found to exhibit greater behavioral concerns, especially in the face of pre-existing issues [12]. Increased physical activity has been suggested as one mechanism by which increased symptoms can be managed in these patients [13].

Academic and Social Challenges Associated With School Closure

Children and young people spend a large proportion of their weekdays at school. Schools provide structure, intellectual stimulation, peer interaction, reliable meals, and access to recreational facilities and health care. Despite attempts to maximize online learning during lockdown, school closures are likely to have many unintended and potentially serious consequences on the psychological and physical health of children and young people [14,15]. Thousands, if not millions, of children from lower socioeconomic backgrounds may be disproportionately affected by school closures and experience food insecurity and inadequate or limited access to online learning [16,17]. Others are likely to engage in increased screen time and sedentary behaviors, just as during longer school holidays [18], placing themselves at risk of unhealthy weight gain [19]. Youth with pre-existing mental health conditions are especially reliant on psychological support services offered through schools and will be unable to access school counsellors, nurses, and social workers [20].

Increased Risk of Family Stress, Domestic Violence, and Abuse

It is well established that increased family stress, financial insecurity, and cumulative risk exposure in childhood are associated with worse mental and behavioral outcomes in children [21,22]. Of particular concern, it is well documented that domestic violence is more likely in the face of chronic family stress such as caring for a child with a CHC. Moreover, chronic family stress further increases following crises such as natural disasters or disease outbreaks associated with economic stress [23-25]. Due to the focus on competing issues, vulnerable children including those with CHCs are often less likely to be identified via routine child health checks and by personnel such as health care professionals or school teachers. Coupled with the significantly reduced number of child protection assessments conducted during lockdown [26], it is likely that COVID-19–associated lockdown, school closures, and family financial insecurity will compound family stress levels and increase the incidence of domestic violence and child abuse [14,27], many of whom unfortunately may not be recognized to receive appropriate support.

Reduced Access to Physical and Psychosocial Support

During the past few months, a significant decline in general practitioner appointments, specialized care, and pediatric emergency department attendance has been reported in many countries including the United Kingdom, Ireland, Germany, Canada, Australia, China, and Italy [28-35]. In some cases, delays in seeking treatment and lack of specialized care have had devastating effects on children with serious and life-threatening health complications including those of a psychological nature [36,37].

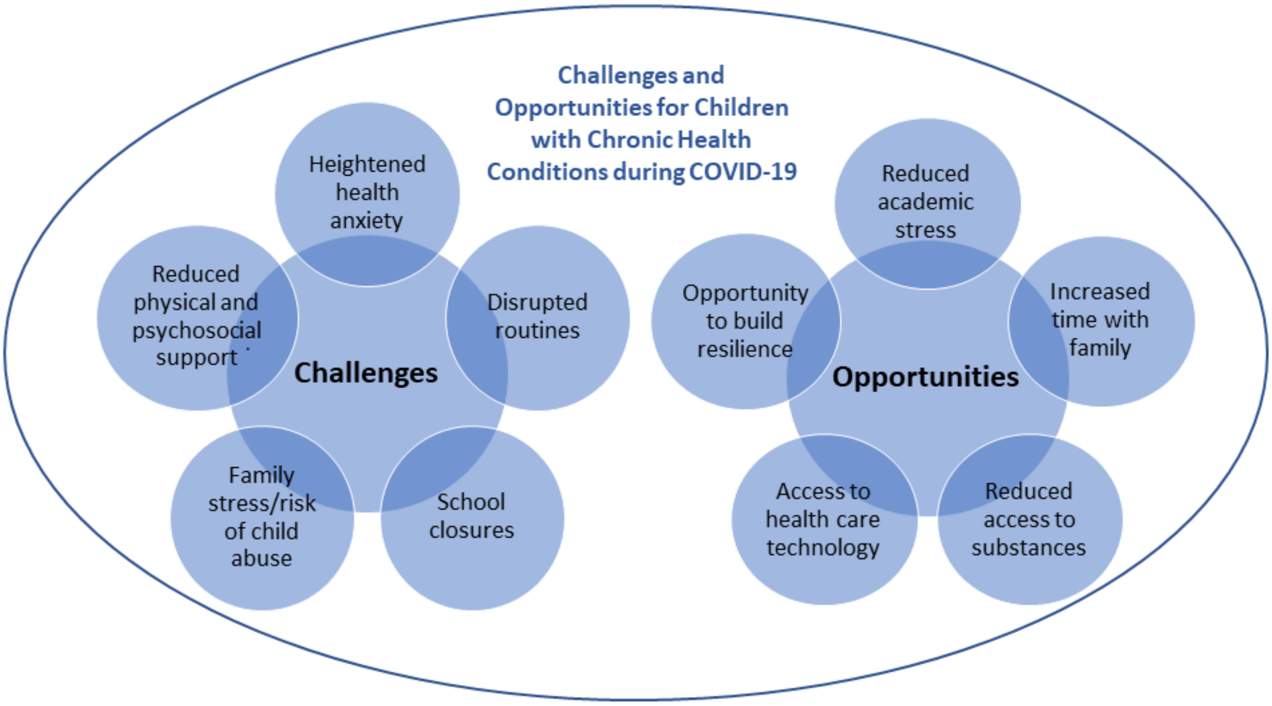
Other reported disruptions to health care services include disruptions to routine child health services, such as developmental screening, vaccinations, and well-child visits, that support psychosocial well-being [31,33]. There is also accumulating evidence to suggest that children with certain CHCs have been negatively impacted by changes to health care systems prioritizing the response to the pandemic, such as inflammatory bowel disease [38], pediatric cancer [39,40], and type 1 diabetes [41].

Previously limited psychological services for children and young people with CHCs are also likely to have been affected by COVID-19–related disruptions. Countries such as Singapore have reported diverting psychological resources for youth with eating disorders to only those considered most urgent and forging partnerships with community services to manage the decrease in access to psychological therapies [42], while other countries such as New Zealand have restricted face-to-face pediatric consult liaison services to inpatients at low risk of COVID-19. In the United Kingdom, 26% of young people with pre-existing mental health problems reported being unable to access psychological support services during the lockdown period [9].

Psychosocial Opportunities

Although children and young people with CHCs are at risk of all the previously mentioned challenges, they may also benefit in the following ways: reduced academic and social stress, increased time with families, reduced access to substances, easier access to health care using technology, and opportunities to build resilience. We discuss these opportunities in more detail in the following sections and a summary is included in Figure 1 along with related challenges.

Figure 1. Opportunities and challenges for children with chronic health conditions during COVID-19.



Reduced Academic and Social Stress

Although some degree of academic pressure may be essential for learning, the chronic stress of regular assignments, presentations, and examinations can have negative effects on students' physical and psychological health, including precipitating conditions such as anxiety, depression, and eating disorders [43,44]. Associated with the developmentally congruent drive toward conformity, adolescent peer-related stress can also affect students' health in a gender-related manner [45]. Youth with CHCs experience additional stresses related to disrupted education and peer relationships, readjustment during transitions in and out of the hospital, and the physical limitations of ill health [46]. During lockdown, all these issues are likely to occur less frequently. Additionally, for some, such as children with cystic fibrosis, the normalization of wearing masks may reduce the sense of difference and associated stigma [47].

Increased Time With Families

Many children will be forced to spend weeks, if not months, with their families during lockdown. Given that domestic *social capital* has been shown to be more influential than school-related social capital and that it is associated with a reduced incidence of behavior problems [48], including in people with chronic illness [49], it is possible that many children and young people with CHCs will benefit from their parents being more available, being more involved in health care routines, and supporting them to deal with COVID-19–related or other health concerns. Family-based therapies for eating disorders [50] and other conditions may also be more effective in the context of greater parental availability. Additionally, evidence from Austria indicates that social connectedness can increase during lockdown and that it is associated with reduced distress and fatigue [51].

Reduced Access to Substances

Up to 40% of young people with CHCs have issues related to substance abuse [52]. Pandemic-related anxiety, fear, and boredom are likely to increase the drive toward substance-related coping in this subgroup. Smoking and inhaling substances are particularly likely to increase the risk of contracting COVID-19 [53]. Fortunately, these risks are likely to be offset by reduced access to substances and, to a lesser extent, by lower financial independence and greater parental connection [54].

Easier Access to Health Care Using Technology

Due to disruptions to routine services, health professionals worldwide have had to rapidly adopt or expand digital health care via Zoom (Zoom Video Communications, Inc), Skype (Skype Technologies), and other servers or platforms. Regulatory barriers to telemedicine have also been amended due to the urgency caused by the pandemic [55]. Despite some of the limitations associated with engagement and physical examination, the necessity for patients to have access to digital devices, and the potential loss of privacy for young people, digital health care is likely to have equitably increased access to health care for many families, especially those living rurally and with limited financial means. It is also likely to have reduced the anxiety experienced by some children in medical settings and allowed health professionals to gain a better understanding of their patients' living circumstances. The pandemic may provide an additional opportunity to expand the use of existing eHealth interventions such as evidence-based internet cognitive behavioral therapy (iCBT)–based applications, medical support, and self-management interventions [56], and to identify ways for future interventions to improve outcomes for youth with CHCs.

Opportunities to Build Resilience

Resilience has been defined as the ability of an individual to withstand adversity [57]. Despite the medically and socially related stresses they experience on a day-to-day basis, most children and adolescents with CHCs manage to live productive and effective lives, thereby demonstrating their inherent resilience [52]. The current pandemic is likely to provide them with additional opportunities to withstand novel concerns about their health; alterations to health care and other routines; increased family stress; and disappointment about missing out on schooling, peer interactions, and leisure activities. With adequate family, social, and health professional support, previous studies have proved that children with CHCs can surmount significant periods of difficulty [58].

Recommendations for Future Research and Clinical Care

We offer the following recommendations and considerations for future research:

- Longitudinal studies of physical and psychosocial well-being, including rates of common mental health problems such as anxiety, depression, self-harm, and substance use disorders as well as rates of hospitalization and suicide, should be conducted across all age groups. Although a number of these studies are already underway and listed on websites such as Covid Minds [59], we noted that few studies are specifically targeted toward youth with CHCs.
- Prospective or retrospective analyses of high-risk subgroups including those with ADHD and ASD should be undertaken.
- Examination of the short- and long-term effects of school closure on personal stress, social relationships, and health care should occur.
- Analysis of the impact of the naturalistic increase in time spent with families, especially in regard to conditions such as eating disorders where social capital is integral to treatment, should be considered.
- Investigation of rates of domestic violence and abuse, particularly in families already experiencing chronic health-related stress, is necessary.
- In-depth qualitative analysis should be conducted regarding the views of patients of all ages, families, and health professionals regarding the use of digital health care, with a view to informing future service design and workforce development.
- Evaluation of the effectiveness of existing digital interventions should be planned as well as the co-design and development of locally and culturally acceptable new interventions for addressing COVID-19–related issues.
- Specific examination of resilience should be carried out using validated outcome measures, not merely assuming its existence in the absence of pathology.
- Economic analyses should be conducted to ascertain the direct and indirect costs of pandemic-related disruption and inform planning for future events of a similar nature.

In the meantime, to optimize the clinical care of children and young people with CHCs, we provide some resources and recommend readers to:

- Support families to access generic advice on how best to care for children and young people during the pandemic from organizations such as the World Health Organization [60] and, where available, more specific health-related advice via sources such as the International Society for Pediatric and Adolescent Diabetes [61], immunology and cancer services [62-64], and the Cystic Fibrosis Trust [65]
- Encourage families to maintain essential health care routines and to present early via appropriate channels when they have concerns about their children's well-being
- Opportunistically screen for psychological issues, especially anxiety and depression, during clinical contacts using paper-based instruments such as the Generalized Anxiety

Disorder scale-7 items and the Patient Health Questionnaire-9 item or electronic methods such as YouthCHAT [66,67]
- Refer those with identified issues early to available psychological services, either face-to-face or via tele-health
- Recommend the use of evidence-based digital self-help, iCBT, and peer support interventions; for an up-to-date list of these, refer to websites such as One Mind PsyberGuide [68]
- Encourage parents and health professionals to engage in self-care to reduce the likelihood of burnout and to sustain effective support of children and young people with CHCs during and following the pandemic

Conclusion

Although the full impact of the COVID-19 pandemic on children and young people with CHCs might not be understood for a long time to come, increased awareness of the likely challenges and opportunities faced by this group and an integrated approach to their care [1] are likely to optimize their psychosocial well-being. Leveraging digital health interventions is key to addressing some of these challenges and opportunities in this vulnerable population [69]. The current circumstance also offers a unique opportunity to examine and improve a range of aspects pertaining to their care, and we sincerely hope that it provides the silver lining to a long dark cloud.

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Conflicts of Interest

None declared.

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Abbreviations

ADHD: attention-deficit/hyperactivity disorder
ASD: autism spectrum disorder
CHC: chronic health condition
iCBT: internet cognitive behavioral therapy

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Original Paper

Social Media Use and Monitoring for Adolescents With Depression and Implications for the COVID-19 Pandemic: Qualitative Study of Parent and Child Perspectives

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Abstract

Background: Although youth report many positive experiences with social media (SM) use in their daily lives, adolescents with depression are more vulnerable to the risks of SM use than adolescents without depression. Parents protect adolescents with depression from the risks of SM use by monitoring their child's SM activity; however, this comes into conflict with the adolescent's need for autonomy in their web-based communication. The implications of SM use and monitoring for adolescents with depression and their parents are of particular relevance to the COVID-19 pandemic, as rates of SM use have increased in response to physical distancing measures.

Objective: This study aims to explore parent and child perspectives regarding the use and function of SM in the daily lives of adolescents with depression and parents' perceptions of and experience with monitoring their child's SM use.

Methods: We conducted qualitative interviews with adolescents with depression (n=23) and one parent of each adolescent (n=23) between July 2013 and September 2014. The adolescents were patients seeking treatment for depression in Pittsburgh, Pennsylvania. Data analysis included dyadic analysis of the adolescents' and parents' perspectives and qualitative descriptions of individual parent interviews to explore their experiences with SM use and monitoring. The construct of parental knowledge and factors hypothesized to contribute to parental knowledge, including adolescent disclosure, parental solicitation, and parental control, were used to guide the codebook and dyadic data analysis.

Results: Dyadic analyses showed that parents and their children disagreed on the use and function of SM in the daily lives of adolescents with depression, with adolescents viewing SM as a forum for honest expression of their emotions, whereas parents felt that their children's posts were inconsequential and interfered with the adolescents' lives. Furthermore, parents reported using a wide range of strategies to gain knowledge of their child's SM use to monitor their safety on SM, including direct solicitation and indirect solicitation, such as keeping the child's passwords, asking friends or siblings about their child's SM use, and restricting SM behavior and access to devices.

Conclusions: Clinicians should support adolescents with depression and their parents in finding common ground for an effective and acceptable monitoring approach. Resources are provided for clinicians navigating conversations about SM use and monitoring with adolescents with depression and their parents during the COVID-19 pandemic.

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KEYWORDS

social media; adolescent; parents; depression; disclosure; qualitative research; COVID-19

Introduction

Background

Adolescents are widely reported to be ubiquitous users of social media (SM). As of 2018, 70% of US adolescents reported using SM multiple times per day, a rate that has doubled from reports in 2012 (34%) [1]. More than half of parents are concerned that their children spend too much time on their mobile phones and worry about the potential negative effects of screen time in their children’ s daily lives [2]. Parents of adolescents with depression may have unique concerns regarding their children’s ongoing consumption of SM, as they perceive heightened susceptibility to harmful experiences [3].

Adolescent SM Use During the COVID-19 Outbreak

The use of SM during the COVID-19 pandemic is estimated to have increased substantially. In their analysis of SM use from web-based data providers, *TheNew York Times* reported that the use of the popular SM sites Facebook and YouTube increased by 27% and 15%, respectively [4]. Increasing rates of SM use may be especially meaningful to young people, as physical distancing measures limit face-to-face interaction. Deprivation of peer interactions, in particular, is challenging during adolescence, a developmental stage during which peer influence and acceptance are important [5]. In the face of these concerns, SM may play an influential role. Studies of adolescent SM use show that aspects of prosocial face-to-face interactions that are protective to adolescent mental health, such as social support, social reward, and reduction of feelings of social exclusion, can be mirrored through active engagement on SM [5]. Although SM may play an important role in mitigating limitations to social interaction during the pandemic, there are also concerns associated with higher rates of SM activity. Prevention groups have raised concern that stress associated with the pandemic could contribute to higher rates of negative SM experiences, such as cyberbullying [6]. The potential for harmful SM interactions is complicated by reduced access to counseling and mentorship from educators [6]. In the current context, considering adolescents’ SM use and the ways in which parents monitor their use is significantly important.

Use of SM in Adolescents With Depression

Adolescents with depression face vulnerabilities that place them at a higher risk of having negative SM experiences and unique opportunities for social support and connection than youth who are not depressed. Adolescents with depression use SM in positive ways; for example, engaging in entertainment, humor, or content generation can act as a distraction from depressed mood [7], and these adolescents can also reach out to others for support in coping with depression or for social connection [8]. With regard to vulnerability to negative SM experiences, adolescents with depression are more likely to engage in risky SM behavior, such as talking to strangers and disclosing personal information [9], and to be exposed to potentially harmful SM content, such as self-harming behaviors [10,11]. In addition, youth with depression are more likely to report internet harassment [12], cyberbullying [13,14], and addictive internet use [15] experiences that have been associated with fluctuations in mood states and heightened suicidal risk among adolescents [16-20]. Parents of adolescents in treatment for depression or suicidal risk have reported awareness of their child’s heightened vulnerability to negative SM experiences and describe an urge to stay informed about their child’s SM use to protect them from harm [3].

Parent and Adolescent Perceptions Toward SM Use and Monitoring

Adolescents and parents often exhibit different perspectives regarding SM use [2]. Adolescents tend to view SM in a more positive light, citing benefits of social connection, social support, and opportunities to express themselves [21]. In contrast, parents report more negative views toward SM considering its potential detrimental effects on youth [21]. The shifting parent-adolescent relationship that is typical of adolescent development may also contribute to these differences in perspectives on SM use. Adolescents seek freedom of expression on SM, whereas parents balance their child’s desire for independence with their own desire to protect their child from risks on SM [22]. Discrepancies in these views are likely to be unique when considering adolescents with depression and their parents. For example, adolescents with depression may value support they receive through SM and autonomy in privately engaging with trusted peers. Parents of adolescents with depression may be more attuned to potential negative aspects of SM use on their child’s depression and may also perceive a strong need to monitor.

Parental Monitoring and Knowledge of Adolescent’s SM Use

Parental monitoring has been defined as the tracking or surveillance of a child’s behavior and is often assessed through measures of parental knowledge [23]. Kerr and Stattin [23,24] hypothesize 3 primary sources of parental knowledge. These sources include (1) adolescents’ voluntary sharing of information with their parents; (2) parents’ solicitation of information from their child; and (3) parents’ use of control, meaning setting rules and restrictions to limit their child’s ability to engage in activities without informing their parents [23,24]. Thus, information sharing between parents and adolescents can occur through dialogue (eg, informal or formal monitoring discussions) or through behaviors (eg, parents’ engagement in mediation of SM as a means to gain control). Of these sources, parental knowledge is most strikingly informed by adolescent disclosure.

Voluntary adolescent disclosure is considered to be a strong and consistent predictor of parental knowledge above and beyond parents’ solicitation of information [25]. By the time of adolescence, youth are developmentally capable of making choices to voluntarily offer private information [26]. Keeping secrets, particularly when negative consequences are perceived, is also developmentally typical and impacted by contextual factors within the family, such as the degree of trust present between parents and adolescents and overall relationship quality [26,27]. Supportive parenting styles exhibited by warmth, affection, and responsiveness to adolescents’ needs are more likely to facilitate voluntary disclosure [28,29]. Unsupportive styles of parenting, such as parenting that involves the use of psychological control or manipulation techniques such as love withdrawal, shaming, or guilt induction, act as barriers to voluntary disclosure [28,29].

Some methods of parental solicitation and control have been associated with reductions in parents' knowledge of their child's SM behavior. Parents' engagement in privacy invasions or the covert solicitation of a child's private information often act as impediments to open parent-child communication. Privacy invasions have been associated with increased adolescent secrecy and deficits in family functioning, for example, problematic communication, behavior, and relationships [30-32]. Engaging in methods of parental control that adolescents may see as a restriction to their freedom of expression also hinders adolescent disclosure and, in turn, increases secrecy [33].

These long-standing trends toward parental knowledge and control remain consistent within media studies. In their meta-analysis, Chen and Shi [34] showed that parents' active engagement with their child's media use, namely, through openly discussing media use or parental co-use of media with their child, was effective in reducing SM risk behaviors. They also found that parental restriction alone was not associated with a reduction in risky behaviors.

Context of Parental Knowledge of SM Use Among Adolescents With Depression

Parental knowledge of SM use is of critical importance for the discussion of depression in adolescents. Open parent-child communication that is fostered through adolescents' voluntary disclosure is associated with reductions in depressed mood, improvements in self-esteem, and positive and realistic expectations toward media use [23,24]. Conversely, parents' engagement in unsupportive communication or deployment of control strategies (eg, setting rules that require their child to share information about their SM use) has been linked to increased depressive symptoms and poorer adjustment among adolescents [23,24,35]. When parents' lack of support takes the form of negative reactions to adolescents' disclosures, adolescents are left feeling disconnected to their parent and respond by engaging in secrecy [33]. Secrecy could be detrimental in situations when a parent may need to intervene to address their child's depressed mood or suicidal thoughts.

Research Gaps

Parents' attempts to understand and explore their child's SM use may be especially challenging in the current era in which SM activity is ubiquitous and trends toward use among adolescents are increasing in the face of the COVID-19 pandemic. Little is known, however, about the context of parental monitoring of SM use among adolescents with depression. Understanding the context of how parents of adolescents with depression balance the unique challenges in weighing their child's unique vulnerabilities toward negative SM experiences and unique opportunities for social support and connection could offer important contributions for clinicians who are partnering with families to support youth with depression. First, similarities and differences in perspectives of adolescents with depression and their parents toward SM use and monitoring have not been explored. Considerations toward monitoring among youth with depression, who are more vulnerable to negative SM experiences, may be distinct from adolescents who are not depressed. Second, strategies that parents of adolescents with depression use to stay informed of their child's SM use are not well understood and may offer helpful guidance to parents of adolescents with depression on how to protect their child while supporting their emerging independence.

The exploration of these findings may be especially beneficial to providers engaged in the mental health care of adolescents who are recommended to assess the harmful and helpful influences of adolescents' digital lives [36]. Providers' ability to accurately assess the SM context is likely to be influenced by parent and child perceptions toward the use and function of SM. Furthermore, providers who wish to partner with parents to observe and protect adolescents' SM environments may face challenges if the child's and parent's preferences toward SM monitoring strategies are discrepant.

Aims

To offer insights for clinical practice with adolescents with depression and their families, we sought to explore the perspectives of youth with depression and their parents toward SM use and monitoring. Through interviews with adolescent and parent dyads, we aim to compare parent and child views toward the use and function of SM use in the daily lives of adolescents with depression. Through interviews with individual informants, we aim to explore parents' strategies and experiences with gaining knowledge of their child's SM use.

Methods

Recruitment and Sampling

As part of a larger qualitative study to inform an intervention using SM for adolescents with depression and their parents [7], a convenience sample of adolescents aged 13 to 20 years diagnosed with depression and currently receiving treatment in Pittsburgh, Pennsylvania, and one parent of each adolescent were invited to participate in interviews. From July 2013 to September 2014, potential participants were informed about the study by clinicians treating patients for depression at 2 sites: (1) an academic adolescent and young adult medicine clinic with mental health services available or (2) a specialty psychiatric clinic for adolescents with depression and suicidality. Of the 31 adolescent-parent pairs (of which there were 31 adolescents and 30 parents because 1 mother had 2 children in the study) who filled out an interest form, 8 adolescents and 7 parents could not be reached for an interview; thus, 23 adolescents and 23 parents completed the study. Of these, there were 21 adolescent-parent matched pairs. One parent had 2 children in the study. Reporting of data collection and analytic methods follows the Consolidated Criteria for Reporting Qualitative Research [37].

Data Collection

All interviews were conducted by the senior author, who was trained and experienced in qualitative data collection and analysis. She introduced herself to adolescents as a researcher and physician in Adolescent Medicine. Semistructured interviews were conducted over telephone (n=17 adolescents and n=17 parents) or in person in a private patient room in the clinical setting (n=6 adolescents and n=6 parents). Parent and child interviews were conducted separately. We obtained verbal consent from parents for themselves and from adolescents aged 18 years and older; for those aged 18 years and younger, we obtained parental permission and adolescent assent. The interviewer assured participants that the research team would guard confidentiality, specifically not sharing phrases said on SM, which could potentially be searched to identify them.

A 30- to 60-minute semistructured interview, facilitated through an interview guide while remaining open to topical trajectories that broadened the understanding of participants' perspectives, was conducted individually with the adolescent alone and then with the parent alone. These interviews were used to obtain information about SM use characteristics and positive and negative experiences with SM use for both adolescents and parents—pertaining to parents' personal use of SM and whether the parent uses SM or the internet to learn more about their child's depression or to connect with other parents. Parents were also asked (1) whether their child uses SM and to describe their positive and negative SM experiences, (2) their opinion of and experiences with their child sharing personal thoughts with others via SM, and (3) their experience communicating with their child through SM. Adolescents were asked about how the type and extent of their SM use varies with their mood. Both adolescents and parents were also asked to provide demographic information, including age, gender and race, length of depression treatment, mobile phone ownership, and primary device for internet use. Questions on SM use characteristics were adopted from Pew Research Center studies on adolescent SM behavior [38,39]. As compensation for study participation, adolescents received a book about adolescent with depression or bipolar disorder [40], and parents received a book about being a parent of an adolescent with depression or a bipolar disorder [41]. The study protocol was approved by the University of Pittsburgh Human Research Protection Office.

Data Analysis

We analyzed interviews of both individual informants and dyads to explore adolescent and parent perspectives toward SM use and monitoring. Such an approach offers the potential to investigate rich contextual factors associated with concordant and discrepant family experiences [42]. Individual interviews are well suited for offering a contextual analysis that sheds light on perspectives from a specified group [43]. Exploration among dyads can enrich findings from individual interviews by offering an ability to compare across multiple perspectives, which is known to improve the trustworthiness of findings [43] and to identify discrepancies and disagreements. All interviews were audiotaped; transcribed verbatim, removing any participant identifiers; and coded using ATLAS.ti version 7, a qualitative analysis program manufactured by Scientific Software Development [44].

Dyadic Analysis of Interviews With Parents and Adolescents

As the original focus of this study did not include dyadic-level analyses, a direct comparison approach could not be used because of differences in questions asked of adolescents and their parents. However, during the analysis of parent and adolescent interviews, similar descriptions of events or ideas by parents and their children created an organic opportunity to examine dyadic-level themes by way of content analysis. Using the Eisikovits and Koren model of dyadic analysis [43], matched adolescent-parent dyadic transcripts were reviewed by horizontalization and cross-analysis for overlaps and contrasts between text, subtext, descriptive, and interpretive levels, with the description of an event that occurred in SM (eg, cyberbullying of the adolescent from the perspective of the adolescent and from the perspective of the parent) as the unit of analysis. Dyadic transcripts were reviewed by independent coders (the first and second authors) who noted these horizontal themes, and discrepancies were settled by team consensus.

Analysis of Individual Interviews With Parents

The data analytic approach to the description of parents' experiences with their child's SM use used the technique of qualitative description. As described by Sandelowski [45], qualitative description refers to a thematic content analysis where findings aimed to stay close to the data as opposed to being overly interpretative. Using a content analysis approach [46], the first 4 interviews were reviewed independently by 2 investigators using an initial codebook based on the interview script. An updated list of codes focusing on key areas of interest was generated, with additional review by a senior member of the research team. Subsequently, the rest of the interviews were coded by 1 investigator and then reviewed by the senior author who made additions and/or changes. Additions of new codes or changes in code definitions were determined via consensus among the research team. The final sample size was determined by content saturation, which refers to the point at which adequate information is gathered to meet the purposes and goals of the research [47].

Results

Participant Characteristics

Of those who completed the study (23 parents and 23 adolescents), the average age for adolescents was 16 years (range 13-20 years) and the average age for parents was 46 years (range 37-55 years). Most adolescents (18/23, 78%) and most parents (19/23, 83%) were female, and most adolescents (20/23, 87%) and parents (21/23, 91%) were White (3/23 adolescents, 13%, and 2/23 parents, 9%, were African American), which reflects the demographics of patients seeking care for depression at the 2 sites. At the time of enrollment, adolescents on average had received treatment for depression over 25.4 months (range 3-84 months). Most parents (19/23, 83%) and adolescents (22/23, 96%) used SM. Parents most frequently reported using Facebook (18/23, 78%), whereas adolescents' SM use was more diverse across platforms (10/23, 43%, used Facebook and 4/23, 17%, used Twitter, Tumblr, and Instagram).

Dyadic Analysis of Parent and Adolescent Interviews

We first summarized themes based on dyadic analysis of the interviews, on which we directly compared child and parent interpretations of shared events. This analysis aimed to understand parents' and adolescents' mutual and divergent interpretations of adolescents' use of SM in their daily lives. These themes included SM as a form of expression, the function of SM, SM as a space to discuss depression with others, interacting with strangers on SM, and parental monitoring of adolescents' SM use.

SM as a Form of Expression

Parents and adolescents generally disagreed on SM being a medium for individual expression. Adolescents viewed SM as a forum for honest expression of themselves and their emotions, whether positive or negative. Adolescents elected to express themselves through song lyrics that capture their emotions or what adolescents described as ranting about an event that happened to them. Parents, however, saw much of what their adolescent was posting on SM as inconsequential or something to do when they felt bored and that it could interfere with other activities in the adolescent's life. These themes are demonstrated in the following quotes from a parent and child dyad who had divergent views on adolescents' SM expression:

> *Just to post like whatever you want. Because it's your Twitter, so you can just say how you feel, like what you're doing that day. Just anything in general really. Like anything that you want. So, it shouldn't matter like what you post.* [Child perspective; age 16 years]
>
> *But when I saw what she—all the song lyrics she was putting on there, that caused me to have concern and... I just brought it up. And she thought it was funny. And she's, and you know—I said, 'I don't understand why you want to put these lyrics out there,' because they weren't good lyrics. And she says, 'Well, I'm expressing myself.' And I say, 'But why do you have to tell everybody? Like why'—I don't get it. I just don't get the whole thing. I'm just old-fashioned.* [Parent perspective]

Positive and Negative Functions of SM

Some parents and adolescents mutually described the potential of SM to be a protective, healing, or supportive space or a place to seek positive content. In other cases, parents and adolescents both offered clear examples of and reflections on the harms of SM use. For example, one parent was concerned about posts or forums that encourage self-harm behaviors (eg, cutting), which aligns with her daughter's concerns—who had a history of intentional self-harm—and was worried that such forums or posts would encourage her daughter to cut herself. Other examples had greater discrepancy, which typically occurred when one member of the pair was more ambivalent and the other had a stronger point of view. The following quotes present discrepant perspectives between a parent and child dyad on the use and utility of SM:

> *So I think that if I do something on that website, like if I make an edit to just something that I enjoy and I'm interested in, that's something that's good, and I can read the feedback that I get from it. And so as long as I'm busy rather than if I look up the tag of #sad, that might make me more sad. But it's kind of like, I get some sort of satisfaction from looking at sad pictures because it's something I can relate to, which is kind of weird.* [Child perspective, age 14 years]
>
> *She spends an inordinate amount of time. And while the people on there, cool, some of them have the same experiences and stuff, she's also not getting the face-to-face social stuff that I think she really needs, especially somebody going through what she's going through as far as the depression.* [Parent perspective]

SM as a Problematic Space to Discuss Depression With Others

Some parents and adolescents agreed that it was safer, more private, and more authentic to talk about depression with trusted friends offline; however, their reasoning was not always the same. Parents were concerned about negative consequences and expressed distrust with others on SM, or they preferred that their child talk to them directly. Adolescents, on the other hand, expressed worry about what others would think—that posting on SM would draw unwanted attention, be burdening to others, or simply felt it was not others' business. These viewpoints are demonstrated by the following parent and child dyad:

> *I don't want everybody to know my business, like what I'm dealing with on like a really personal level...a family member might see it and, well, they might tell another family member about it and it would just go around the whole family.* [Child perspective; age 17 years]
>
> *My thought's that if they feel that way, he should come to his mother and father and talk to them about it instead of putting it out there for everybody else. Some people is cruel, and they'll end up saying something that'll make him worse.* [Parent perspective]

Risks and Benefits of Anonymous Interactions on SM

Parents and adolescents had differing opinions about talking with strangers or interacting anonymously on SM. Parents expressed concern over their child being friends or having followers that were strangers or the lack of privacy in SM. In contrast, adolescents perceived that having strangers as friends on SM was not problematic and normative. These divergent perspectives are described by the following parent and child dyad:

> *I think it's because I was just younger and I didn't care who I was friends with, or you know, like you want to have so many friends on there so you just add whoever, type of thing.* [Child perspective; age 17 years]
>
> *How dangerous it is, and, you know, some of these people are older, 20s, 30s, they 're men. How she doesn't need to be, they don't need to see her pictures, they don't need to know anything about her, they don't know her period, that people are dangerous, you can't trust any, you know, everybody. You know, that people can find out anything they want to know.* [Parent perspective]

Parents' Monitoring of Adolescents' SM Use

Parent and adolescent perspectives on monitoring were predominantly divergent. In some cases, parents' attempts to view their child's SM content to prevent negative experiences left adolescents feeling resentful, particularly when the adolescent was excluded from this process (eg, a parent looking though their child's phone without the adolescent's permission). Furthermore, when parents restricted SM use, some adolescents defied their parents' wishes by creating secret accounts on SM or by engaging with strangers. In other cases, parents considered monitoring strategies that would protect the parent-child relationship, which might include having honest conversations with their child about privacy or safety issues surrounding sharing of information on SM. These efforts corresponded with adolescents citing examples of choosing not to disclose private matters on SM; however, adolescents rarely contributed their decisions regarding privacy to their parents' monitoring efforts, as is exemplified in the following quotes from a parent and adolescent dyad:

> *I really do think that she's too smart to share it with strangers. I mean, I really think I've educated her in that, you know, strangers are never your friends, and they're not who they say are—I think she's wiser than her years when it comes to that, but I'm sure a lot of parents think that and then something tragic happens.* [Parent perspective]
>
> *If it's something private, I think—I mean just from my opinion, I think, I just keep it to myself...I think that people would see it and just kind of like, maybe feel bad or like—and I just feel that they would know my personal business. And it's just like not necessary.* [Child perspective]

Analysis of Individual Parent Interviews

Drawing from the frequent divergent interpretation of adolescents' SM use and behaviors, themes were explored to identify the ways in which parents of youth with depression within this sample gain knowledge of their child's SM use and parents' attitudes and experiences with SM monitoring.

Parental Expectations

Parents had a variety of expectations both toward their adolescents' capacity to use SM in a healthy manner and in the potential of monitoring to have an impact on their child's SM use. Parents generally expected their child to use SM in a way that was healthy. As described in the following quote, some parents felt that their expectations were met, describing a sense of trust in their child to create and maintain prosocial SM relationships and to express their opinions and experiences of depression in a way that is healing:

> *I trust her, you know, quite a bit, really—I mean, fully—with the use of it. I think she's got a good head on her shoulders, and, so, yeah, I think she's managing her own positive experience of it.*

Alternatively, other parents' expectations were unmet. They also had concerns that their adolescent was engaging in maladaptive behaviors such as oversharing (or being too trusting of sharing personal information on SM), which parents believed may have negative consequences, such as bullying, embarrassment, or future impact, on employment opportunities. Some informants were surprised to find their child's peers discussing risky behavior on SM (eg, sharing sexually explicit content). One parent offered an example of discomfort with photos shared by her child's friends:

> *...my daughters have a lot of friends with inappropriate photographs, and I don't think that they think they're inappropriate, but...I don't think teenage girls should be in bathing suits on the internet.*

In addition, parents expressed both positive and negative expectations that their monitoring efforts would actually have an impact on their adolescents' engagement with SM. Some felt capable of intervening to improve their adolescent's SM interactions, for example, having an open conversation about cyberbullying. Alternatively, others were concerned that SM was too difficult to regulate or control and that intervening would be ineffective. The following quote offers an example of a parent's negative expectation:

> *...it's not a battle I choose to fight. I'm not going to—you can't—the internet in general is basically an unlimited freedom. You can see and do just about whatever your imagination can come up with.*

Adolescent's Disclosure to Their Parents

Descriptions or perceptions that adolescents are telling their parents about their SM use or the impact of SM use on their mood varied. In some cases, when adolescents accepted their parent's monitoring, they were willing to openly discuss their SM use and its impact on them with their parents. One parent offered an example of her child openly disclosed information about her SM use:

> *...she's pretty—[name] is I would say much more open with me than, than I, than certainly I ever was with my parents...I just felt like my mom was so far, you know, like way into my business in the first place, that I didn't share, but [name] and I have a, have a pretty good relationship, I think and like she has no problem. Like she'll come to me for advice and say, 'What should I say to this person?'*

Selective disclosure of behaviors was also observed, meaning that adolescents hid some aspects of their SM use from their parents in fear of a negative consequence. In these cases, adolescents feared that negative SM experiences may lead to parents deactivating their SM accounts, or they fear their parents will respond with rejection or disapproval.

Parental Knowledge

Several parents found it difficult to be knowledgeable about their children's SM behavior. As described in the following quote, parents reported being unaware of which platforms their child used and did not know if their adolescent was bypassing their rules regarding SM use:

> *I asked her not to get on Facebook anymore. And then she snuck, and she got on Facebook a second time, using a different name.*

Some parents acknowledged that their adolescents had hidden concerning SM interactions from them. For example, one parent noted that her daughter hid photos posted on SM of her self-injuring:

> *Before she had her attempt of suicide, she had a GifBoom account that was very dark, and we didn't find out about it until later, but like had pictures of cutting—it almost was like a support group for that.*

Other parents were more secure in their knowledge of their child's SM interactions, and at times, this impacted adolescents' SM behavior, often reducing personal content disclosed on SM. In the following quote, a parent described how their child being aware of familial monitoring corresponded with reduced sharing on SM:

> *Well, I have to be honest, she doesn't really share too much online from a Facebook standpoint, regarding how she feels or her depression, because she has many family members who are her friends on Facebook. And I think, and I'm trying to get into her mind, and I'm thinking that she doesn't put a lot of that out there because of who they are. Like if it's her Nana, which is her grandmother, or her grandfather, or her aunts and uncles, she doesn't put a lot of that out there, because she knows that they will read it.*

Parental Solicitation

To gain knowledge of their child's SM use, parents engaged in solicitation. In some cases, solicitation involved directly asking the child about their SM use. Parents engaged in this direct form of solicitation both in person and on SM, predominantly in instances when they felt their child was having negative experiences on SM or based on a belief that SM was inherently harmful (eg, contributing to their depression or encouraging risky behavior). Parents not using this direct form of solicitation described not wanting to *hover* or be controlling and preferred trusting in their child to maintain healthy SM behavior.

Parents also engaged in indirect forms of solicitation, which may have included a parent looking through their child's phone or knowing the password to their SM accounts. Some parents felt this was an important way to learn previously unknown information about their child, such as new disclosures of risk-taking behavior described on SM or even to have a window to how the child feels or experiences their depression in a way that adolescents may not communicate with their parents. In the following quote, a parent described her experience with learning the utility of SM in providing information on her child's emotional state:

> *Her father and I both were very against her sharing these things online, or really even, we kind of wanted her to just not even have an online account or anything. But then we kind of were, I don't know, awakened to the fact that this is kind of the only window you have into your kid's emotions sometimes. You know, teenagers especially don't like to tell their parents what's going on or to talk about how they're feeling. And sometimes that's how you see how they're really feeling, is by some of the stuff they're posting, even if they don't realize that they're showing it, you can kind of just see their different moods. I think it definitely has given us some, I don't know, opportunities to talk that maybe we wouldn't have had before. Especially—it's very easy for kids to just come home and say, 'Yep, school was fine. I'm fine.' And the that's it, you know.*

Adolescents were more accepting of indirect forms of monitoring when there was an agreement between the parent and child of how this would be done. For example, one adolescent noted that their parent having their account password information led to openness in communication surrounding SM. To protect their child's privacy and the parent-child relationship, some parents used other sources such as asking a friend, sibling, or other relative to assist in monitoring or using monitoring software.

Parental Control

Efforts to control adolescents' behaviors included restricting sites perceived to be harmful and attempting to restrict certain SM behavior. One parent described how their efforts to restrict their child's SM use were brought about by a desire to protect their child from harmful SM content:

> *Honestly right now, at this point in time, I have blocked most of the social networking sites from my daughter because of some of the things that I have seen on her wall and some of the things that I have seen that she posted. Because she's going through this, let's call it a difficult time in her life right now, I don't think that she needs to rehash and read, and see all these different things because it's just open—everything that is imaginable is on these social networking, and I just, I'm—I guess I'm trying to, to the best of my ability, is to protect her from seeing these different things...*

Furthermore, some parents limited their adolescent's SM use after their child did something of which they disapproved. Disciplinary actions included restricting access to a certain SM site entirely or taking the child's phone away. In the following quote, a parent related her experience with restricting her child's access to Facebook:

> *So, I asked her not to get on Facebook anymore. And then she snuck and she got on Facebook a second time, using a different name. And the same thing was happening...so then finally after she did it the third time, we told her absolutely, positively not. She wasn't allowed to go even into Facebook to read it, to read anybody's comments, to even talk to anybody. She's not, at this point she's not allowed on Facebook at all.*

Rule setting was enforced through both direct and indirect means of solicitation, including the use of monitoring software or by asking designated members of the child's social network (eg, a friend of the parent who is monitoring the adolescent on behalf of the parent). Attempts to restrict SM behavior varied by age, where some parents restricted the use of certain SM sites or any site before a certain age. Parents who did not engage in restriction reported a sense of powerlessness or loss of control. One parent described how she wished she could set rules but felt doing so would be ineffective and could damage her relationship with their child:

> *I wish I had the nerve to tell her she wasn't allowed to use it but it would just be such a barrier and it would just make her hate me and not talk to me, and there's no point—like I said, like I prepare her for the adult world, in a year and a half she'll be at college, and I don't want her to go off the deep end then and say, 'My mother would never let me do this, so now I'll show her...'*

Another parent described a perception that attempts to control are ineffective and correspondingly a sense of lack of control:

> *We tried at first to completely like eliminate her having them, but we found that when you do that they just kind of find ways to do it behind your back, and then you have no way to know what's going on. So, she voluntarily will show me a lot of this stuff. You know, I still do fear that there's things out there that I'm not seeing. But I don't know if there's ever a way to monitor 100%. You're almost kind of kidding yourself if you think you are.*

Discussion

Principal Findings

This study uses rich qualitative inquiry to explore child and parent perspectives toward SM use and monitoring for adolescents with depression. Our study describes the experiences of adolescents with depression using SM to seek autonomy from their parents and the parents attempt to maintain knowledge of their child's SM use to offer protection because of concerns of a potentially unsafe environment for their vulnerable child. Although previous research has described the struggles between adolescents' and parents' overuse of SM [22], this study's dyadic analysis of the perspective of adolescents with depression and their respective parents is unique. SM presents challenges through risky SM behaviors, negative SM experiences such as cyberbullying, and worsening mood [11,39,48,49], to which adolescents seeking clinical treatment for depression are especially vulnerable. SM also presents opportunities for social connection and supportive interactions, which are especially important for youth facing depression [50]. Conflict over the use of SM in the context of depression may create added challenges that youth without depression and their parents or caregivers may not have to address. This study offers findings that have implications for clinicians engaged in the treatment of adolescents with depression, who are heavy users of SM. Especially in the current context of the COVID-19 pandemic, clinical guidance for parental monitoring of SM is critical.

The findings from the dyadic interviews showed that although a few parents and adolescents agreed about the use and function of SM, most had discrepant perspectives. Discrepancy often stemmed from a difference in value placed on autonomous SM expression versus protection from the risks of SM use. These views can be considered with a report released from the United Nations International Children's Emergency Fund [51], which considers children's rights for digital privacy. In accordance with the United Nations Convention on the Rights of the Child [52], this report suggests that children have a right to digital privacy and that parents have a dual responsibility—both to protect their adolescent from web-based threats and to encourage free expression by their adolescent in web-based spaces. This dual responsibility appears to create conflict and discrepant views between adolescents and their parents.

For parents attempting to balance this dual responsibility, United Nations International Children's Emergency Fund's report suggests the extent to which privacy and access to SM is given should be considered based on the child's evolving capacity, for example, their age and maturity level. In the case of adolescents with depression, a child's capacity may also include the potential for heightened vulnerability to harmful SM experiences. At the same time, adolescents with depression report finding value in having a venue to express themselves emotionally and receive support through trusted SM friends. Furthermore, some studies found that these protective interactions had a healing effect, which positively influenced their mood. This suggests that although parents should take measures to protect their child from SM-related risks to their safety, they should also look for opportunities to allow their children to engage freely, particularly with supportive peers on SM.

The results of the individual interviews can be placed within the context of conceptualization of parental knowledge by Kerr and Stattin [23]. The sources of parental knowledge they have identified—*adolescent disclosure, parental solicitation, and parental control*—appear to be salient in understanding how parents engage in surveillance and monitoring of SM behavior of adolescents with depression. Consistent with the literature [25,26], adolescents voluntarily disclosed information about their SM use to their parents when they accepted their parents' monitoring strategies but were less likely to disclose when they perceived the potential for a negative consequence. When teens felt comfortable, they were willing to discuss their SM use and its impact on their mental health with their parents. Due to concerns about their children engaging in risky SM behavior, several parents were keenly interested in gaining information either by directly asking their child about their SM use or through overt or covert methods of viewing their child's actual SM content. Parents' engagement in covert forms of solicitation are potentially concerning because privacy invasions have been associated with increased secrecy and lower parental knowledge [31,32]. Parents engaged in a variety of control techniques, that is, rule setting surrounding their child's SM use and, in some cases, violation of parents' rules resulting in disciplinary actions. When parents engaged in controlling behaviors without their child's knowledge or buy-in, teens were not entirely honest with their parents about their SM experiences. When parents engaged in privacy invasions, adolescents became secretive and, in some cases, engaged in risky SM behavior without their parents' knowledge.

These results suggest that there is a unique context for parents of adolescents with depression for engaging in SM monitoring and unique consequences for their child's acceptance of their chosen monitoring strategies. The positive consequences of open parent-child communication that fosters voluntary disclosure are significant. Parents can be more aware of their child's SM activity to protect them from the negative influences of SM while fostering positive influences. Likewise, the negative consequences of SM monitoring strategies that contribute to a lack of knowledge are also considerable. As was evident in these interviews, when adolescents with depression do not accept their parents' use of SM monitoring, they have the potential to withhold information from their parents about risky SM communication, such as posting about self-harm or communicating with strangers. Lacking such information stifles parents' capacity to protect their child from harm. Further, restriction techniques that limit access to supportive SM interactions may have the consequence of reducing the protective influences of SM.

Implications for the Clinical Care of Adolescents With Depression

Understanding parent and child perspectives toward SM use and strategies parents deploy to learn about the SM activity of their child with depression could offer valuable insights toward clinical intervention planning. For example, the strategies parents use to procure information about their child's SM use could either support or discourage the child's voluntary disclosure of risky SM interactions or negative experiences. Such voluntary disclosure may be the most effective way for parents and clinicians to be knowledgeable about the level of risk within the child's SM environment. In addition, adolescents' voluntary disclosure to parents could result in a greater awareness of the protective aspects of their SM use, including sources of support that adolescents with depression may find critical to preventing their depressed mood from worsening. Understanding the context of adolescents and parents' perspectives toward SM use and monitoring could aid clinicians in opening lines of discussion that validate both parties' unique concerns to move toward the goal of an effective and acceptable monitoring approach.

In 2019, the American Association of Suicidology (AAS) [36] released recommendations for parents and providers engaging in SM monitoring of adolescents at risk for suicide. According to the recommendations by AAS, clinicians should engage in a risk assessment of both the helpful and harmful influences of adolescents' engagement with SM and use this information to build a crisis intervention safety plan. It is considered a best practice for safety plans to be developed by clinicians in collaboration with parents. When engaging in risk assessment, clinicians should consider ways by which SM can offer meaningful opportunities for emotional expression and support for adolescents with depression and work with parents to consider how engaging in restrictive strategies could affect these helpful aspects of SM use. Clinicians should offer parents caution with strategies that involve privacy invasions that have the potential to weaken parent-child connections and may have the unintended consequence of placing children at higher risk. The risk assessment should also consider potential negative influences of SM, such as exposure to harmful or hateful content, and engage adolescents in considering ways to openly discuss negative SM experiences with their parents.

The Family Media Plan developed by the American Academy of Pediatrics [53] may be instrumental in developing a mutually agreeable plan for parents and adolescents. This plan offers an opportunity for open discussion about critical topics such as screen time, use at important times of day such as while doing homework or before bed, appropriateness of media content, and rules for digital safety. Clinicians could be trusted confidants to adolescents with depression and their parents when considering these topics and work together with the family to find a middle ground between parents' desire for protection and adolescents' desire for autonomy toward a mutually acceptable monitoring approach.

Implications for the COVID-19 Pandemic

The unique context of the COVID-19 pandemic is especially relevant and important for the SM use and parental monitoring of adolescents with depression. Our data reflect the importance that adolescents with depression place on maintaining prosocial SM peer interactions. During the pandemic, when youth face challenges associated with the loss of face-to-face social interaction, maintaining connection with supportive peers on SM is important to mitigate feelings of social isolation, a significant risk factor for suicide [5,54]. At the same time, parents of youth with depression, who our data reflect are concerned about their child's exposure to negative SM experiences, may be especially worried about heightened risks associated with adolescents' increased SM activity. This context places a demand on parents to monitor their adolescents' SM use; however, this comes into conflict with significant economic, social, and health challenges that affect families' daily lives [55].

As adolescents and their parents face unprecedented challenges, clinicians of youth with depression have an important role in helping families find a balance between concerns for safety on SM and autonomous communication with peers. Given the risk of social deprivation that ongoing physical distancing measures may have on adolescents, clinicians should work with parents to consider risks of limiting their child's access to supportive SM peers, while also offering guidance to reduce exposure to negative SM content (eg, cyberbullying or conversations or images pertaining to self-harm). Clinicians may benefit from using resources from Common Sense Media, which provide guidance for parents in safeguarding their children's physical and mental wellness as they access digital media during the pandemic [56]. In addition, the Suicide Prevention Lifeline's collection of web-based resources to support healthy coping during the COVID-19 outbreak may be beneficial contributions to safety plans for adolescents facing pandemic-related mental health challenges [57].

Strengths and Limitations

A key methodological strength of this study was the conduct of separate interviews with parent and child dyads, which allowed for analysis at both the individual and dyad levels. First, the separate analysis of parent and child interviews allows each informant to tell the story from their own perspective [43]. As adolescents and their parents often have incongruent views of the same events [58], dyadic interviews provide an opportunity to highlight conflicting perspectives on SM use and monitoring. Second, the collection of separately conducted parent and child interviews helped capture the individual within the dyad, without sacrificing the dyadic perspective [43]. Finally, the ability to triangulate perspectives at both an individual level and dyad level increases the capacity to broaden knowledge and contextual understanding of a phenomenon [43].

This study offers a unique contribution to the literature by exploring parent and child perspectives toward SM use and monitoring of adolescents with depression. Despite the novelty of this study, it has limitations. First, this study was not intended to be a dyadic analysis of how both parents and their adolescents with depression perceived the adolescent's use of SM. Some aspects of the parent-child relationship related to SM use and monitoring may be unknown because they were not shared during the interviews. Second, the sample is predominantly White and female and from an academic medical institution, where many of the patients visiting the clinic may have had more severe forms of depression and, therefore, may not be representative of adolescents with depression and their respective parents. Moreover, these same patients were brought to the clinic by their parents, suggesting that these parents may be more proactive in their children's health, which may include their child's SM use. Third, the same interviewers conducted these dyadic interviews. In this situation, although the interviewer assured confidentiality and interviewed participants separately, the other party was virtually present in the interview space. This may make the other party (whether parent or adolescent) be selective of what they will tell the interviewer [43]. Finally, we have framed the relevance of these findings within the COVID-19 pandemic that has observed a sharp increase in SM use alongside a diminishment of parents' availability for monitoring [59]; however, these data were collected before the pandemic's onset. Therefore, potential differences in adolescents' and parents' perspectives toward within the current context and the evolving nature of SM use may not be represented. Despite these limitations, this study provides helpful insights into the challenges adolescents with depression and their parents face in approaching safety and acceptable SM monitoring.

Conclusions

Our interviews described the experiences of adolescents with depression and their respective parents on adolescents' use of SM in their daily lives, a topic that bears particular relevance during the COVID-19 pandemic when SM use has risen dramatically in response to physical distancing measures. The findings highlight the conflict over adolescents' growing need for autonomy versus the parents' need to protect their child with depression because of concern for their child's heightened vulnerability to the risks of SM use. Parents try to balance these 2 components by obtaining knowledge of their child's SM use through their child's voluntary disclosure, by soliciting information from their child, or through parental control techniques. Our study has highlighted the need for clinicians to partner with families to identify mutually agreeable monitoring strategies that meet both the parents' desire to be knowledgeable about their vulnerable child's SM use and the adolescents' need for independence in their SM interactions.

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Conflicts of Interest

None declared.

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Abbreviations

AAS: American Association of Suicidology

SM: social media

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Original Paper

Parental Acceptability of COVID-19 Vaccination for Children Under the Age of 18 Years: Cross-Sectional Online Survey

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Abstract

Background: It is expected that COVID-19 vaccines will become available in China by the end of 2020. Vaccinating children against COVID-19 would contribute to the control of the pandemic and the recovery of the global economy. For children under the age of 18 years, parents are usually the decision makers regarding their children’s vaccination.

Objective: The goal of this study was to investigate parental acceptability of free COVID-19 vaccination for children under the age of 18 years in China.

Methods: This is a secondary analysis of a cross-sectional, closed online survey among 2053 factory workers in Shenzhen, China, implemented from September 1 to 7, 2020. Participants of the online survey were full-time employees aged 18 years or over who had resumed work in factories in Shenzhen. Factory workers in Shenzhen are required to receive physical examinations once a year. Eligible workers attending six designated physical examination sites were invited to complete an online survey. This study was based on a subsample of those who had at least one child under the age of 18 years (N=1052). After being briefed that COVID-19 vaccines developed by China are likely to be available by the end of 2020, participants were asked about their likelihood of having their children under the age of 18 years take up free COVID-19 vaccination provided by the government, if it existed. Multivariate logistic regression models were fitted to examine the associations of perceptions related to COVID-19 vaccination based on the theory of planned behavior (TPB) and exposure to information related to COVID-19 through social media with parental acceptability, after controlling for significant background characteristics.

Results: The prevalence of parents’ acceptability of COVID-19 vaccination for their children was 72.6% (764/1052). After adjusting for significant background characteristics, positive attitudes toward COVID-19 vaccination (adjusted odds ratio [AOR] 1.70, 95% CI 1.50-1.91), the perception that a family member would support them in having their children take up COVID-19 vaccination (ie, perceived subjective norm) (AOR 4.18, 95% CI 3.21-5.43), and perceived behavioral control to have the children take up COVID-19 vaccination (AOR 1.84, 95% CI 1.49-2.26) were associated with higher parental acceptability of COVID-19 vaccination. Regarding social media influence, higher exposure to positive information related to COVID-19 vaccination was associated with higher parental acceptability of COVID-19 vaccination (AOR 1.35, 95% CI 1.17-1.56). Higher exposure to negative information related to COVID-19 vaccination was negatively associated with the dependent variable (AOR 0.85, 95% CI 0.74-0.99).

Conclusions: Parents’ acceptability of COVID-19 vaccination for their children under 18 years of age was high in China. The TPB is a useful framework to guide the development of future campaigns promoting COVID-19 vaccination targeting parents.

Transparency in communicating about the vaccine development process and vaccine safety testing is important. Public health authorities should also address misinformation in a timely manner.

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KEYWORDS

parental acceptability; COVID-19 vaccination; children under the age of 18 years; theory of planned behavior; social media influence; China

Introduction

Globally, the COVID-19 pandemic remains out of control [1]. The existing measures to control COVID-19 are detrimental to the global economy [2] and result in significant impairment in physical and psychological well-being [3]. There is a strong need for an effective vaccine to keep COVID-19 under control. Development of COVID-19 vaccines is underway. According to the World Health Organization, as of September 3, 2020, there were 34 and 142 candidate vaccines in clinical and preclinical evaluation, respectively; four Chinese candidate vaccines had entered Phase III clinical trials [4]. According to an official press release on September 15, 2020, safety of these Chinese candidate vaccines was established [5]. The National Health Commission of the People's Republic of China authorized the emergency use of COVID-19 vaccines on July 22, 2020 [6]. COVID-19 vaccines were provided to workers, students, and diplomatic personnel who needed to travel abroad, as well as to health care workers and personnel working for pandemic and border control [5]. It is expected that at least one COVID-19 vaccine will become available in China by the end of 2020 [5,7,8].

The United States National Academies of Sciences, Engineering, and Medicine has proposed a five-phase plan to fairly allocate a COVID-19 vaccine. Health care workers, older adults, and other people with underlying conditions that put them at high risk of severe COVID-19 diseases or death are priority groups to receive the vaccine, followed by essential workers, children, and young adults [9]. Without COVID-19 vaccination, children will likely serve as a reservoir, which would undermine efforts to end the pandemic [10]. Moreover, it is difficult to recover the economy completely before all children can safely return to schools and parents can resume full-time work [10]. According to the aforementioned official press release, health care workers, older adults, and children are considered priority groups to receive COVID-19 vaccination in China [5].

Mathematic modeling suggested that if the COVID-19 vaccine efficacy was 80%, the coverage would have to achieve at least 75% to extinguish the ongoing pandemic [11]. Therefore, a timely understanding of community responses to the forthcoming COVID-19 vaccines are important for policy making and service planning. For children under the age of 18 years, parents are usually the decision makers regarding their children's vaccination. Hence, it is important to understand parents' acceptability of their children's COVID-19 vaccination and related barriers and facilitators. To our knowledge, at least one study investigated parents' acceptability of COVID-19 vaccination for their children [12]. This was an online survey conducted in the United Kingdom, which showed that 48.2% of parents or guardians would definitely accept COVID-19 vaccination for their children aged 18 months or under [12]. Belief that COVID-19 vaccination could protect their children and other family members and belief that it would facilitate their return to normal life were major reasons for parents' acceptance of COVID-19 vaccination for their children [12]. Their concerns were around COVID-19 vaccine safety and effectiveness [12]. These factors were considered by this study. We applied the theory of planned behavior (TPB) as the theoretical framework in this study [13]. The TPB postulates that behavioral intention to adopt a health-related behavior (eg, having children take up COVID-19 vaccination) is a strong predictor of actual behavior. In order to form such an intention, one would evaluate the pros and cons of the behavior (ie, positive and negative attitudes), consider whether their significant others would support such behavior (ie, perceived subjective norm), and appraise how much control one has over the behavior (ie, perceived behavioral control) [13]. In recent studies, the TPB has been used successfully to explain vaccination behaviors [14-16].

Previous studies showed that people are actively seeking information about COVID-19 vaccination on social media platforms [17]. Exposure to COVID-19–specific information on social media influenced Chinese factory workers' adoption of personal preventive measures (eg, face mask wearing, hand hygiene, and physical distancing) [18]. Moreover, different content related to COVID-19 may have varying effects on health outcomes [18]. A previous study suggested that TPB-related constructs and subsequent behavior may be shaped by the use of social media [19]. In this study, we investigated the associations between exposure to different content related to COVID-19 vaccination on social media and parental acceptability of having their children vaccinated.

To our knowledge, there have been no studies investigating parental acceptability of COVID-19 vaccination for their children in China. This study investigated parental acceptability of free COVID-19 vaccination for children under the age of 18 years among parents in Shenzhen, China. We examined the effects of factors on their acceptability, including background characteristics, perceptions related to COVID-19 vaccination based on the TPB, and exposure to information related to COVID-19 vaccination through social media.

Methods

Study Design

This is a secondary analysis of a cross-sectional, closed online survey among 2053 factory workers in Shenzhen, China, implemented from September 1 to 7, 2020.

Participants and Data Collection

Participants of the closed online survey were full-time employees of factories in Shenzhen aged 18 years of age or older. This study was conducted in Longhua District of Shenzhen. The majority of factories in Shenzhen are located in Longhua District; there were over 2000 factories and one million factory workers in 2018 in this district. In Shenzhen, factory workers are required to receive physical examinations at designated sites once a year. All six designated sites providing physical examination services to factory workers in Longhua District, including three public hospitals, two private hospitals, and the district Centre for Disease Control and Prevention (CDC), were chosen as our study sites for recruitment.

To avoid selection bias, the fieldworkers approached all adults attending these sites for physical examinations during the study period. They briefed prospective participants about the study details, confirmed their eligibility, and invited them to join the study. Participants were guaranteed that participation was voluntary, refusal would have no effect on them, the survey would not collect personal contact information or identification, and data would be kept strictly confidential and would only be used for research purposes. Verbal consent was obtained instead of written consent to allow participants to maintain anonymity. We developed an online questionnaire using Questionnaire Star (Changsha Ranxing Information Technology Co), a commonly used online survey platform in China. Quick response (QR) codes were generated to access the online questionnaire. Prospective participants were asked to scan the QR code on-site to complete the survey. Each mobile device was allowed to access the online questionnaire once to avoid duplicate responses. The participants were asked not to disseminate the QR codes that were used to access the survey to other people. The survey had 66 items, approximately 15 items per page for four pages, which took about 15 minutes to complete. The online survey platform performed completeness checks before each questionnaire was submitted. Participants were able to review and change their responses through a *back* button. In case there was more than one child under the age of 18 years within their household, participants referred to the one whose birthday was closest to the survey date when answering questions [20]. Upon completion of the survey, an electronic coupon of ¥10 (US $1.30) was sent to participants. All data were stored in the server of the online survey platform and were protected by a password. Only the corresponding author had the access to the database.

Out of 2653 eligible factory workers being approached, which included between 60 and 1200 across the study sites, 2053 completed the online survey, which amounted to between 40 and 968 across the study sites. The overall response rate was 77.4% (2053/2653); this ranged from 66.7% to 80.7% at different sites. Main reasons for nonresponse were lack of time and other logistic reasons. This study was based on 1052 participants who had at least one child under the age of 18 years. Ethics approval was obtained from Longhua District CDC (reference No. 2020001).

Measures

Development of the Questionnaire

A panel consisting of one CDC staff member, two public health researchers, a health psychologist, a senior factory manager, and a factory worker was formed to develop the questionnaire used in this study. The questionnaire was pilot-tested among 10 factory workers to assess clarity and readability. These 10 workers did not participate in the actual survey. Based on participants’ comments, the panel revised and finalized the questionnaire.

Background Characteristics

Participants were asked to report on sociodemographics (ie, age, gender, relationship status, education level, monthly personal income, etc), age of their children, parental history of seasonal influenza vaccination, and whether they had a family member with a history of COVID-19. In addition, participants were asked to report on their frequency of wearing face masks when having close contacts with others in the workplace and in other public settings (ie, public spaces and transportation) in the past month; response categories included *every time*, *often*, *sometimes*, and *never*. Participants also reported on the frequency of sanitizing their hands using soaps, liquid soaps, and alcohol-based hand rubs after returning from public spaces, touching public installations, and touching equipment, and whether they avoided social and meal gatherings with people who do not live together as well as crowed places in the past month.

Parental Acceptability of Free COVID-19 Vaccination for Children Under the Age of 18 Years

Participants were briefed with the following statement: “COVID-19 vaccines developed by China are likely to become available by the end of 2020.” They were then asked about the likelihood of having their children under the age of 18 years take up free COVID-19 vaccination provided by the government, if it existed; response categories included the following: 1 (very unlikely), 2 (unlikely), 3 (neutral), 4 (likely), and 5 (very likely). Parental acceptability of COVID-19 vaccination was defined as the responses *likely* or *very likely*. Such definition has been commonly used in previous studies [20,21].

Perceptions Related to COVID-19 Vaccination Based on the TPB

Two scales were constructed to assess perceptions related to COVID-19 vaccination based on the TPB. These scales were the 3-item Positive Attitude Scale (eg, “COVID-19 vaccination is highly effective in protecting your child from COVID-19”) and the 4-item Negative Attitude Scale (eg, “Your child will have severe side effects after receiving COVID-19 vaccination”); response categories were as follows: 1 (disagree), 2 (neutral), and 3 (agree). The Cronbach α values of these two scales were .71 and .64, respectively; single factors were identified by exploratory factor analysis, explaining 64.0% and 56.6% of the total variance, respectively. Perceived subjective norm (ie, “Your family member will support you in having your child take up COVID-19 vaccination”) and perceived behavioral control (ie, “Having your child receive COVID-19 vaccination is easy for you if you want them to") were measured by two single items; the response categories were as follows: 1 (disagree), 2 (neutral), and 3 (agree).

Influence of Social Media

Participants were asked to report on the frequency of their exposure to information related to COVID-19 vaccination on social media (ie, WeChat, WeChat Moments, Weibo, TikTok, etc) in the past month; response categories were as follows: 1 (almost none), 2 (seldom), 3 (sometimes), and 4 (always). Such information included (1) positive information related to COVID-19 vaccination (eg, new vaccines entering clinical trials), (2) negative information related to COVID-19 vaccination (eg, concerns about vaccine efficacy, supply, and side effects and about the receipt of vaccines causing COVID-19), (3) testimonials given by participants of the COVID-19 clinical trials, and (4) negative information about vaccine incidents in China (eg, selling problematic vaccines and severe side effects).

Statistical Analysis

Parental acceptability of COVID-19 vaccination was used as the dependent variable. A univariate logistic regression model first assessed the significance of the association between each of the background characteristics and the dependent variable. Background characteristics with *P*<.05 in the univariate analysis were adjusted in a multivariate logistic regression model. Principal component analysis with varimax rotation was used to perform explanatory factor analysis. SPSS Statistics for Windows, version 26.0 (IBM Corp), was used for data analysis, with *P*<.05 considered statistically significant.

Results

Background Characteristics

Over half of the participants were 40 years old or younger (824/1052, 78.3%), were female (658/1052, 62.5%), were married (1005/1052, 95.5%), did not receive tertiary education (785/1052, 74.6%), had a monthly income level lower than ¥5000 (US $714) (703/1052, 66.8%), and were frontline workers (701/1052, 66.6%). Among the parents, 20.0% (210/1052) had received seasonal influenza vaccination in the past and 0.2% (2/1052) had at least one family member with a history of COVID-19. About half of their children were 0 to 6 years of age (490/1052, 46.6%).

In the past month, 72.1% (759/1052) and 83.1% (874/1052) of participants reported wearing a face mask every time they had close contact with other people in the workplace and in other public settings, respectively. Fewer participants self-reported sanitizing their hands (606/1052, 57.6%), avoiding social and meal gatherings (622/1052, 59.1%), and avoiding crowed places (697/1052, 66.3%) (see Table 1).

Table 1. Background characteristics of the parents.

Characteristics	Value (N=1052), n (%)
Sociodemographics	
Age of the parent (years)	
18-30	238 (22.6)
31-40	586 (55.7)
>40	228 (21.7)
Gender	
Male	394 (37.5)
Female	658 (62.5)
Relationships status	
Married	1005 (95.5)
Currently single or divorced	43 (4.1)
Having a stable boyfriend or girlfriend	4 (0.4)
Highest education level attained	
Junior high school or below	448 (42.6)
Senior high school or equivalent	337 (32.0)
College or university or above	267 (25.4)
Monthly personal income (¥)	
<3000	238 (22.6)
3000-4999	465 (44.2)
5000-6999	185 (17.6)
7000-9999	90 (8.6)
≥10,000	74 (7.0)
Type of work	
Frontline worker	701 (66.6)
Management staff	351 (33.4)
History of seasonal influenza vaccination	
No	842 (80.0)
Yes	210 (20.0)
Having at least one family member with a history of COVID-19	
No	1050 (99.8)
Yes	2 (0.2)
Age of the child (years)	
0-3	314 (29.8)
4-6	176 (16.7)
7-12	373 (35.5)
13-17	189 (18.0)
Personal COVID-19 preventive measures in the past month	
Frequency of face mask wearing in public places and on transportation other than the workplace	
Every time	874 (83.1)
Often	139 (13.2)
Sometimes	36 (3.4)
Never	3 (0.3)

Characteristics	Value (N=1052), n (%)
Frequency of face mask wearing when you have had close contact with other people in the workplace	
Every time	759 (72.1)
Often	204 (19.4)
Sometimes	82 (7.8)
Never	7 (0.7)
Self-reported sanitizing of hands, using soaps, liquid soaps, or alcohol-based sanitizer, after returning from public spaces or touching public installations	
Every time	606 (57.6)
Often	277 (26.3)
Sometimes	156 (14.8)
Never	13 (1.2)
Self-reported avoiding of social and meal gatherings with other people who do not live together	
No	430 (40.9)
Yes	622 (59.1)
Self-reported avoiding of crowed places	
No	355 (33.7)
Yes	697 (66.3)

Parental Acceptability, Perceptions, and Influences of Social Media Related to COVID-19 Vaccination

Among the parents, the prevalence of parental acceptability of free COVID-19 vaccination was 72.6% (764/1052) (see Table 2). Individual item responses and mean (SD) values of the scales related to parental perceptions of COVID-19 vaccination are presented in Table 2. Among the participants, 69.3% (729/1052) were sometimes or always exposed to positive information related to COVID-19 vaccination in the past month. Among the participants, fewer were sometimes or always exposed to negative information related to COVID-19 vaccination (442/1052, 42.0%) or vaccine incidents in China (298/1052, 28.3%), or were sometimes or always exposed to testimonials given by participants of COVID-19 vaccination clinical trials (283/1052, 26.9%) (see Table 2).

Table 2. Perceptions related to COVID-19 vaccination.

Acceptability and perceptions	Value (N=1052), n (%) or mean (SD)
Parents' acceptability of COVID-19 vaccination for their child under the age of 18 years: likelihood of having the child take up free COVID-19 vaccination, n (%)	
Very unlikely	19 (1.8)
Unlikely	45 (4.3)
Neutral	224 (21.3)
Likely	361 (34.3)
Very likely	403 (38.3)
Perceptions related to COVID-19 vaccination based on the theory of planned behavior	
Positive attitudes toward COVID-19 vaccination	
Positive Attitude Scale[a] score, mean (SD)	8.0 (1.2)
COVID-19 vaccination is highly effective in protecting your child from COVID-19 (agree), n (%)	603 (57.3)
Taking up COVID-19 vaccination can contribute to the control of COVID-19 in China (agree), n (%)	896 (85.2)
China will have an adequate supply of COVID-19 vaccine (agree), n (%)	763 (72.5)
Negative attitudes toward COVID-19 vaccination	
Negative Attitude Scale[b] score, mean (SD)	7.7 (1.6)
Your child will have severe side effects after receiving COVID-19 vaccination (agree), n (%)	104 (9.9)
The protection of COVID-19 vaccines will only last for a short time (agree), n (%)	210 (20.0)
Your child is afraid of vaccination (agree), n (%)	216 (20.5)
You do not have time to take your child for COVID-19 vaccination (agree), n (%)	234 (22.2)
Perceived subjective norm related to child's COVID-19 vaccination: your family member would support you in having your child take up COVID-19 vaccination	
Response score, mean (SD)[c]	2.5 (0.6)
Agree, n (%)	542 (51.5)
Perceived behavioral control to have the child take up COVID-19 vaccination: having the child receive COVID-19 vaccination is easy for you if you want them to	
Response score, mean (SD)[c]	2.3 (0.7)
Agree, n (%)	456 (43.3)
Influence of social media related to COVID-19 vaccination	
Frequency of exposure to positive information related to COVID-19 vaccination (eg, new vaccines entering clinical trials, promising efficacies of the vaccines, and vaccines will enter the market soon) on social media	
Response score, mean (SD)[d]	2.9 (0.9)
Almost none, n (%)	107 (10.2)
Seldom, n (%)	216 (20.5)
Sometimes, n (%)	420 (39.9)
Always, n (%)	309 (29.4)
Frequency of exposure to negative information related to COVID-19 vaccination (eg, concerns about efficacies and supplies, side effects of the vaccines, and receiving vaccines will cause COVID-19) on social media	
Response score, mean (SD)[d]	2.3 (0.9)
Almost none, n (%)	244 (23.2)
Seldom, n (%)	366 (34.8)
Sometimes, n (%)	327 (31.1)
Always, n (%)	115 (10.9)

Acceptability and perceptions	Value (N=1052), n (%) or mean (SD)
Frequency of exposure to testimonials given by participants of the COVID-19 vaccine clinical trials on social media	
Response score, mean (SD)[d]	1.9 (1.0)
Almost none, n (%)	503 (47.8)
Seldom, n (%)	266 (25.3)
Sometimes, n (%)	185 (17.6)
Always, n (%)	98 (9.3)
Frequency of exposure to negative information about other vaccine incidents in China (eg, selling problematic vaccines and severe side effects) on social media	
Response score, mean (SD)[d]	2.0 (1.0)
Almost none, n (%)	433 (41.2)
Seldom, n (%)	321 (30.5)
Sometimes, n (%)	207 (19.7)
Always, n (%)	91 (8.7)

[a] Response categories for the 3-item Positive Attitude Scale were as follows: 1 (disagree), 2 (neutral), and 3 (agree). Cronbach α=.71; one factor was identified by exploratory factor analysis, explaining 64.0% of the total variance.

[b] Response categories for the 4-item Negative Attitude Scale were as follows: 1 (disagree), 2 (neutral), and 3 (agree). Cronbach α=.64; one factor was identified by exploratory factor analysis, explaining 56.6% of the total variance.

[c] Response categories were as follows: 1 (disagree), 2 (neutral), and 3 (agree).

[d] Response categories were as follows: 1 (almost none), 2 (seldom), 3 (sometimes), and 4 (always).

Factors Associated With Parental Acceptability of COVID-19 Vaccination

In the univariate logistic regression analysis, age of the children, self-reported avoiding of social and meal gatherings with other people who do not live together, and self-reported avoiding of crowed places were significantly associated with parental acceptability of COVID-19 vaccination (see Table 3).

Table 3. Associations between background characteristics and parental acceptability of free COVID-19 vaccination (N=1052).

Characteristics	Crude odds ratio (95% CI)	*P* value
Sociodemographics		
Age of the parent (years)		
18-30	1.0	
31-40	1.23 (0.89-1.72)	.21
>40	1.35 (0.90-2.03)	.14
Gender		
Male	1.0	
Female	0.96 (0.73-1.27)	.79
Relationship status		
Married	1.0	
Currently single or divorced	1.44 (0.68-3.05)	.34
Having a stable boyfriend or girlfriend	1.15 (0.12-11.08)	.91
Highest education level attained		
Junior high school or below	1.0	
Senior high school or equivalent	1.14 (0.83-1.57)	.42
College or university or above	0.98 (0.70-1.38)	.92
Monthly personal income (¥)		
<3000	1.0	
3000-4999	0.95 (0.67-1.34)	.76
5000-6999	1.01 (0.66-1.56)	.95
7000-9999	1.03 (0.60-1.79)	.91
≥10,000	1.26 (0.68-2.32)	.46
Type of work		
Frontline worker	1.0	
Management staff	0.92 (0.69-1.22)	.57
History of seasonal influenza vaccination		
No	1.0	
Yes	1.35 (0.94-1.92)	.10
Having at least one family member with a history of COVID-19		
No	1.0	
Yes	N/A[a]	N/A
Age of the child (years)		
0-3	1.0	
4-6	1.26 (0.84-1.91)	.26
7-12	1.41 (1.01-1.97)	.046
13-17	1.28 (0.86-1.91)	.23
Personal COVID-19 preventive measures in the past month		
Consistent face mask wearing in public places and on transportation other than the workplace		
No	1.0	
Yes	1.31 (0.93-1.86)	.13
Consistent face mask wearing when you have close contact with other people in workplace		
No	1.0	

Characteristics	Crude odds ratio (95% CI)	*P* value
Yes	1.29 (0.96-1.73)	.10
Sanitizing hands (ie, using soaps, liquid soaps, or alcohol-based sanitizer) every time after returning from public spaces or touching public installations		
No	1.0	
Yes	1.10 (0.84-1.45)	.49
Self-reported avoiding of social and meal gatherings with other people who do not live together		
No	1.0	
Yes	1.70 (1.30-2.24)	<.001
Self-reported avoiding of crowed places		
No	1.0	
Yes	1.58 (1.27-2.22)	<.001

[a] N/A: not applicable.

After adjusting for these significant background characteristics, positive attitudes toward COVID-19 vaccination (adjusted odds ratio [AOR] 1.70, 95% CI 1.50-1.91), perceiving that a family member would support them in having their children take up COVID-19 vaccination (AOR 4.18, 95% CI 3.21-5.43), and perceived behavioral control to have the children receive COVID-19 vaccination (AOR 1.84, 95% CI 1.49-2.26) were associated with higher parental acceptability of COVID-19 vaccination. Regarding social media influence, higher exposure to positive information related to COVID-19 vaccination was associated with higher parental acceptability of COVID-19 vaccination (AOR 1.35, 95% CI 1.17-1.56). Higher exposure to negative information related to COVID-19 vaccination was negatively associated with the dependent variable (AOR 0.85, 95% CI 0.74-0.99) (see Table 4).

Table 4. Factors associated with parental acceptability of a free COVID-19 vaccination (N=1052).

Factors	AOR[a] (95% CI)	*P* value
Perceptions related to COVID-19 vaccination based on the theory of planned behavior		
Positive Attitude Scale	1.70 (1.50-1.91)	<.001
Negative Attitude Scale	0.93 (0.85-1.01)	.09
Your family member would support you in having your child take up COVID-19 vaccination (ie, perceived subjective norm)	4.18 (3.21-5.43)	<.001
Having your child receive the COVID-19 vaccination is easy for you if you want them to (ie, perceived behavioral control)	1.84 (1.49-2.26)	<.001
Influence of social media related to COVID-19 vaccination		
Frequency of exposure to positive information related to COVID-19 vaccination on social media	1.35 (1.17-1.56)	<.001
Frequency of exposure to negative information related to COVID-19 vaccination on social media	0.85 (0.74-0.99)	.03
Frequency of exposure to testimonials given by participants of the COVID-19 vaccine clinical trials on social media	1.07 (0.94-1.23)	.31
Frequency of exposure to negative information about other vaccine incidents in China on social media	0.91 (0.79-1.05)	.20

[a] AOR: adjusted odds ratio; background characteristics with *P*<.05 in the univariate analysis were adjusted in the multivariate logistic regression models.

Discussion

This is one of the first studies investigating parental acceptability of COVID-19 vaccination in China that provides some preliminary data to inform policy making and service planning. About 70% of the Chinese parents accepted COVID-19 vaccination for their children. However, given the gap between acceptability and actual behaviors [22], effective health promotion is needed when COVID-19 vaccines become available in order to achieve high vaccine coverage among children.

Our findings provided empirical insights to inform health promotion development. More attention should be given to parents with younger children and those with lower compliance to physical distancing measures (ie, avoiding social and meal gatherings and crowed places), as they reported lower parental acceptability of COVID-19 vaccination. Parents with children attending primary or secondary schools (ie, 7-17 years of age) might have more concerns about COVID-19 transmission within schools and, hence, have higher motivation to vaccinate their children against COVID-19. Parents with higher compliance to physical distancing measures may have stronger motivation and self-efficacy to protect themselves and their children, and

COVID-19 vaccination is likely to be considered a useful means for protection.

The TPB is a potentially useful framework to guide the development of future programs, as three of four TPB constructs used in this study were significantly associated with parental acceptability in expected directions. It is useful to increase positive attitudes toward COVID-19 vaccination, as this was a facilitator. In addition to the beneficial effect for their children (eg, prevent COVID-19 effectively), health communication messages should also emphasize to parents that having their children take up COVID-19 vaccination would result in herd immunization, which could contribute to COVID-19 control. Building up confidence related to vaccine supply may also be a useful strategy. Over half of participants perceived that their family members would support them in having their children take up COVID-19 vaccination. Such perception was also a facilitator. Future health promotion should enhance parents' knowledge of COVID-19 vaccination and encourage them to discuss their children's vaccination with other family members in order to obtain support from these significant others. It is also useful to enhance perceived behavioral control, as this was another facilitator. There is much room for improvement. Multiple strategies may be applied in future COVID-19 vaccination programs, which may include simplification of the procedures to obtain vaccination and school-based vaccination programs. Relatively few participants had concerns related to side effects, duration of vaccine protection, children's apprehension, or other logistical issues. The associations between these concerns and parental acceptability were not statistically significant. Addressing these concerns might not be useful strategies in future promotion campaigns.

Our findings suggested that COVID-19 vaccination triggered intensive responses on social media among Chinese parents, as about 70% of the participants were sometimes or always exposed to information specific to COVID-19 vaccination on different social media platforms. Exposure to content about positive information related to COVID-19 vaccination, such as promising vaccine efficacy, was associated with higher parental acceptability. This is understandable, as this type of information can increase parents' confidence in COVID-19 vaccines and reduce their concerns. Higher exposure to negative information about COVID-19 vaccination was associated with lower parental acceptability. Previous studies showed that people were more likely to absorb negative rather than positive information during a disease outbreak [23]. Although social media is a powerful tool for disseminating information, there are concerns related to inaccurate data, unverified rumors, and even malicious misinformation on these platforms [24]. A global epidemic of misinformation has been spreading through social media during the COVID-19 pandemic, which might pose challenges for future COVID-19 vaccination programs [25,26]. The findings highlighted the importance of transparency in communicating about the vaccine development process and vaccine safety testing. Public health authorities should also identify and verify misinformation in a timely manner. Studies showed that a major vaccine incident (ie, the Changchun Changsheng vaccine incident) had significantly impaired confidence in vaccines among Chinese people [27]. However, in our study, negative information about these vaccine incidents did not influence parental acceptability of COVID-19 vaccination.

This is one of the first studies investigating parental acceptability of COVID-19 vaccination in China. It used the TPB as a theoretical framework and the sample size was relatively large. However, it has a number of limitations. First, we only included parents who were factory workers, as this was a secondary analysis. In 2018, 34.3% of Shenzhen's population were factory workers [28]. However, failure to include parents with other occupations or those without full-time work was one major limitation of this study and limited the representativeness of our sample. In addition, participants were recruited in one Chinese city. Generalization should be made cautiously. Second, since the study was anonymous and did not collect participants' identification, we were not able to collect information about those who refused to join the study. Parents who refused to join the study might have different characteristics as compared to study participants. Selection bias might exist. Our response rate was relatively high as compared to other online surveys of similar topics [12]. Third, there was a lack of methodological innovation in this study. The aim of this study was to provide timely information to facilitate the promotion and service planning related to COVID-19 vaccination in China. Fourth, we did not ask about parental acceptability that was conditional on different cost scenarios. It is common for the Chinese government to provide free vaccination to priority groups in order to increase coverage. Since children were considered as one of the priority groups to receive COVID-19 vaccination, it is possible for the government to offer free vaccines to this group. Fifth, data were self-reported and verification was not feasible. Recall bias might exist. Participants might also overreport their acceptability due to social desirability. Moreover, most items and scales used in this study were self-constructed based on those from previous studies on parental acceptability of human papillomavirus vaccination in China [20]. The internal reliabilities of these scales were acceptable, but these scales may require external validation. Furthermore, this was a cross-sectional study and could not establish a causal relationship.

In sum, parents' acceptability of COVID-19 vaccination for their children under the age of 18 years was high among Chinese parents. The TPB is a useful framework to guide the development of future campaigns promoting COVID-19 vaccination targeting parents. Enhancing positive attitudes, creating a supportive subjective norm, and increasing parents' perceived behavioral control related to their children's COVID-19 vaccination are potentially useful health promotion strategies. Transparency in communicating about the vaccine development process and vaccine safety testing is important. Public health authorities should also address misinformation in a timely manner.

Conflicts of Interest

None declared.

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Abbreviations

AOR: adjusted odds ratio
CDC: Centre for Disease Control and Prevention
QR: quick response
TPB: theory of planned behavior

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Original Paper

Perceptions and Attitudes Toward Mobile Health in Development of an Exclusive Breastfeeding Tool: Focus Group Study With Caregivers and Health Promoters in the Dominican Republic

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Abstract

Background: Despite growing interest in the use of technology to improve health outcomes in low- and middle-income countries (LMICs), local attitudes toward mobile health (mHealth) use in these settings are minimally understood. This is especially true in the Dominican Republic, where mHealth interventions are starting to emerge. This information is critical for developing effective mHealth interventions to address public health issues, such as low exclusive breastfeeding (EBF) rates, which can lead to poor outcomes. With an EBF rate of 5% in the first 6 months of life, the Dominican Republic has one of the lowest EBF rates worldwide.

Objective: This study aims to describe the current use of information and communication technology (ICT) and to analyze the attitudes and perceptions related to using mHealth interventions among caregivers of children aged ≤5 years and health promoters in the Dominican Republic. Findings can inform mHealth strategies aimed at improving EBF in this, and other, LMICs.

Methods: Participants were recruited from 3 outpatient sites: the Niños Primeros en Salud program at Centro de Salud Divina Providencia in Consuelo (rural setting) and Clínica de Familia La Romana and its program Módulo de Adolescentes Materno Infantil in La Romana (urban setting). Focus groups were conducted with caregivers and community health promoters to identify the use, attitudes, perceptions, and acceptability of mHealth as well as barriers to EBF. Discussions were conducted in Spanish, guided by semistructured interview guides. All sessions were audio-recorded and later transcribed. Thematic content analysis was conducted in Spanish by two bilingual researchers and was structured around a hybrid behavioral theory framework to identify salient themes.

Results: All participants (N=35) reported having a mobile phone, and 29 (83%) participants had a smartphone. Sources for obtaining health information included the internet, physicians and clinic, family and friends, health promoters, and television. Barriers to mHealth use included the cost of internet service, privacy concerns, and perceived credibility of information sources. Participants indicated the desire for, and willingness to use, an mHealth intervention to support breastfeeding. The desired features of a possible mHealth intervention included offering diverse methods of information delivery such as images and video content, text messages, and person-to-person interaction as well as notifications for appointments, vaccines, and feeding schedules. Other important considerations were internet-free access and content that included maternal and child health self-management topics beyond breastfeeding.

Conclusions: There is a high level of acceptance of ICT tools for breastfeeding promotion among caregivers in urban and rural areas of the Dominican Republic. As mHealth tools can contribute to increased breastfeeding self-efficacy, identifying desirable features of such a tool is necessary to create an effective intervention. Participants wanted to receive trusted and reliable information through various formats and were interested in information beyond breastfeeding.

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KEYWORDS

global health; breast feeding; mHealth; mobile phone

Introduction

Background

eHealth resources hold promise for advancing child health in low- and middle-income countries (LMICs) where information and communication technologies (ICT) are ubiquitous [1]. According to the United Nations Development Program, ICT are a set of "goods, applications or services that are used to distribute and exchange information," including radio, television, telephone, computers, mobile phones, and the internet [2]. eHealth is the use of ICT in "support of health and health-related fields, including health-care services, health surveillance, health literature, health education, knowledge and research" [3]. Within eHealth, mobile health (mHealth) explores how "mobile technologies can be best used to enhance access to health services and information and to improve the way health professionals deliver health-related services to the general public" [4]. Understanding caregiver perceptions and attitudes toward using mobile phones for health-related purposes is a critical step in developing mHealth interventions that aim to improve child health outcomes internationally, including infant mortality rates [4,5].

Globally, approximately 45% of all infant deaths under 5 years of age are linked to nutrition-related factors [6]. Early initiation of breastfeeding and effective exclusive breastfeeding (EBF) can significantly reduce infant mortality due to common childhood illnesses such as diarrhea or pneumonia [7,8]. According to data from the World Bank, the Dominican Republic has an EBF rate of infants under 6 months of age at only 5% (2014), which is one of the lowest rates worldwide [9]. The Dominican Republic also has an under-five mortality rate of 29 deaths per 1000 live births (2018), considerably higher than the median of 16 deaths per 1000 live births in Latin America and the Caribbean [10]. To address this significant child health issue, breastfeeding promotion interventions emphasizing early initiation and EBF until 6 months of age are critical. These must be effectively designed and utilized in settings such as the Dominican Republic and other LMICs where challenges persist in providing high-quality, easily accessible EBF care and support [11,12].

Although mHealth interventions have been shown to alleviate barriers and enhance access to care in LMICs, a strategic approach in their development is needed to implement effective mHealth on a larger scale and to study how technology can improve health outcomes [4,13-18]. Recognizing that the field of mHealth is rapidly transforming the delivery of health services around the world, the World Health Organization launched an initiative dedicated to the study of eHealth in May 2005 [19]. The United Nations International Children's Emergency Fund has officially identified "promoting the use of new technologies to more efficiently and effectively serve children, especially the most disadvantaged" as part of its Strategic Plan for 2018-2021 [20]. The literature on mHealth in LMICs has examined the use of technology in health care delivery, health systems development, disease surveillance, and implementation of mHealth-based policies [21-25]. However, caregiver perceptions and attitudes toward using mHealth in a global health setting are poorly understood [26].

Objectives

The specific objectives of this study were to describe the current use of ICT and analyze the attitudes and perceptions toward mHealth among caregivers of children younger than 5 years in the Dominican Republic. Although previous studies [27-30] have also utilized a stakeholder-informed process to guide the development of an mHealth intervention to promote EBF, this study was designed using a combined behavioral theory model. Findings will inform future mHealth interventions that aim to improve EBF rates in the Dominican Republic and other LMICs.

Methods

Institutional Review Board Review

This study was reviewed and granted exemption by the Institutional Review Board at the Children's Hospital of Philadelphia, which determined that this study met the exemption criteria per 45 CFR 46.104(d) 2. The Comité Nacional de Bioética en Salud in Santo Domingo, Dominican Republic, agreed that the study was exempt from full Institutional Review Board review. All study procedures were conducted in accordance with the ethical standards of the Helsinki Declaration of the World Medical Association.

Study Sites

The study was conducted at 3 outpatient clinical sites in the Dominican Republic: the Niños Primeros en Salud (NPS) program at Centro de Salud Divina Providencia in Consuelo and Clínica de Familia La Romana (CFLR) and its Módulo de Adolescentes Materno Infantil (MAMI) program, both in La Romana. These sites were purposefully selected to provide a diverse selection of rural and urban mothers and caregivers of children aged ≤5 years to allow for a richer understanding of varied attitudes and perceptions toward mHealth and experiences with EBF. Each site has a set of distinguishing characteristics. In brief, NPS, CFLR, and MAMI fundamentally aim to address factors that influence child nutrition, such as household food insecurity, chronic illness (specifically HIV), and young maternal age, respectively [31]. NPS provides primary outpatient care to children under the age of 5 years living in some of the poorest neighborhoods, also called *barrios*, in a rural community. CFLR is a large health center that provides primary care services and specializes in HIV care and prevention in the Southwest region of the country. MAMI is a satellite clinic of CFLR that provides prenatal and reproductive health care to adolescents and primary care to children of adolescent mothers up to 1 year of age.

Study Population

Consuelo is a rural municipality of the San Pedro de Macorís province with 30,000 inhabitants [32]. The main industry of the region is agriculture, especially sugar cane production. Many *barrios* in Consuelo lack basic amenities such as indoor plumbing and electricity. The catchment area of La Romana province has a population of 276,000 inhabitants, including 80,000 women aged between 15 to 50 years [33]. An estimated 4000 female commercial sex workers are based in La Romana [33]. In addition to the urban city of La Romana, many sugarcane workers and their families live in *bateyes*, which are underserved sugarcane plantation communities. *Batey* residents include Haitian permanent residents, seasonal migrant workers, and indigent Dominicans [33].

Participants in focus group discussions (FGDs) were stratified into groups of caregivers or community health promoters to encourage comfort and candor, as caregivers may have felt uncomfortable sharing information in front of the promoters. For this study, a caregiver was defined as the mother or female guardian of a child aged ≤5 years receiving care at one of the study sites. Traditionally, health promoters are caregivers selected from within their community to serve as trusted advocates, health educators, and health system navigators for other families in their neighborhood or the surrounding community. CFLR and MAMI health promoters are full-time paid employees, whereas NPS health promoters receive a small stipend for several hours served monthly. As they are considered *experienced parent leaders* in their community, health promoters have a unique perspective on how mHealth can be used to carry out their daily activities.

Eligibility Criteria

The criteria used for participants to be considered eligible to enroll in the study were as follows:

1. Mother or female guardian of a child aged ≤5 years or female health promoter of NPS, CFLR, or MAMI.
2. For caregiver participants, the child is a patient receiving care at NPS, CFLR, or MAMI.
3. Speaks and understands Spanish.

Due to the sensitive nature of breastfeeding, the lead investigators chose to have female gender as inclusion criteria, as well as a female focus group facilitator. It was inferred that mixed-gender groups might inhibit women from candidly discussing their experiences with, and barriers to, EBF.

Sample Size

The sample size was established based on the study team's experiences in group design sessions as well as recommendations for sample sizes in qualitative research [34-36]. Several sources have suggested that well-designed focus groups consist of 6 to 12 participants depending on subject and time limits [37,38]. The rationale for this range stems from the goal that enough participants must be included in the groups for a breadth of information to be captured; however, groups should not be so large that each participant does not have a chance to contribute. Moreover, the goal of a qualitative study should be to have a large enough sample size to uncover a variety of opinions but to limit the sample size at the point of saturation. The final sample size was determined by thematic saturation, the point at which new data no longer appeared to contribute to the findings due to the repetition of themes and comments by participants. Additional focus groups were discontinued when it was determined that saturation was attained.

Recruitment

For potential caregiver participants, the principal investigator (CC) worked with clinic staff and nurses to approach each potential participant at random in the clinic waiting room at each site, explained the nature of the study, and assessed the participant's eligibility using a screening questionnaire. This generated a convenience sample of potential participants who were present in the clinic waiting area at each site on the days when the principal investigator (CC) was available to recruit for the study. Health promoters were recruited either by telephone or in-person at the clinics. All female health promoters were invited to participate. Those who expressed interest in participating were provided with the date, time, and location of the group discussion. As all participants might not be available on the day of the focus groups, several sources suggested over-recruitment by 20% to 50% [39,40], so goal recruitment was 9 participants per group.

Data Collection

Data collection took place between December 2018 and February 2019. Before each FGD, informed consent procedures were administered and written informed consent was obtained, including consent to record FGDs with a digital recorder. Participant confidentiality was assured by using floral-themed names rather than their real names during the FGD so that participants could not be identified in the written transcripts.

Before starting the FGDs, we developed a semistructured FGD guide in English and then translated it into Spanish. Local stakeholders (ie, staff pediatricians, nurses, and other clinic staff) verified and revised the translation of preliminary interview guides. The development of the focus group guide was framed using the extended technology acceptance model (ETAM) [41] constructs, the information-motivation-behavioral skills (IMB) model [42] constructs, and scholarly literature, specifically from previous studies using focus groups as formative research for mHealth interventions in an LMIC [43] and in a high-risk population [44]. These semistructured discussion guides were iteratively refined after each focus group and modified to include new data gathered during discussions. The FGD guide for caregivers was designed to elicit which ICT they use, how they utilize ICT to access health information, what factors discourage and motivate caregivers to seek mHealth tools, and what features would be desired in a potential mHealth intervention. Caregiver groups were also asked to share their perspectives on influencing factors for EBF practices. The FGD guide for health promoters focused on identifying challenges with EBF and suggestions on how mHealth tools might be used to promote effective EBF practices.

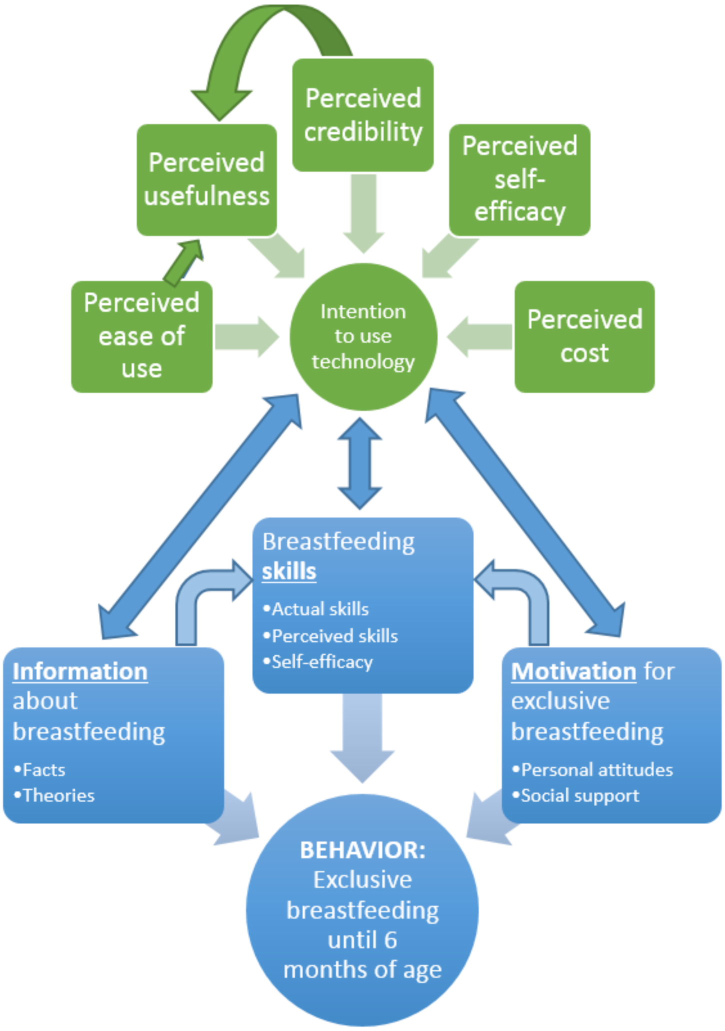
FGDs were facilitated by a trained local research associate and were conducted in Spanish using the FGD guide. Training was provided by one of the senior researchers (LF) who has extensive experience in focus group facilitation. Before each session, a short survey was conducted to collect information on demographics, ICT use, and health information–seeking behaviors. Sessions lasted for 60-90 min and were audio-recorded. The principal investigator (CC) took field notes during each FGD. FGDs were conducted until thematic saturation was reached, as was determined when new information was no longer being obtained during discussions [45].

Data Analysis

All digitally recorded interviews were transcribed verbatim in Spanish by a local transcriber. The transcripts were later professionally translated into English. Any private information accidentally revealed during the focus groups by a participant was removed. Transcripts were reviewed line by line by one of the authors (CC) to assess accuracy, perform framework indexing using the framework method [46], and start formulation of the codebook. A total of 2 authors (CC and SS), who are bilingual in English and Spanish, discussed 2 initial transcripts to refine the development of the codebook. Subsequently, all transcripts were carefully read by CC to develop a list of meaningful units corresponding to the major constructs of the mixed behavioral theory model, which were independently reviewed and discussed with SS. CC and SS then independently coded all transcripts using the established codebook. Coding discrepancies were discussed with LF and EL to obtain consensus. The data were coded using NVivo qualitative analysis software using directed content analysis following the theoretical framework. During coding, any additional meaningful units identified by coders were also identified and continuously discussed between the authors. Codes were arranged by meaning into major themes. Notable quotes pertaining to each theme were organized, discussed, and summarized in a document that presents the findings for each theme.

We chose a directed approach to content analysis through a combined deductive-inductive process to comprehensively review transcripts and identify salient themes [47]. Through deductive use of existing theory in a mixed model of the ETAM and the IMB model (Figure 1) [41,42], we were able to conceptually extend a theoretical framework to help determine the initial coding scheme and relationships between codes, while at the same time, adding any emerging themes from probing or freely shared topics by participants in an inductive approach [47]. In addition, several triangulation categories were used to enhance the reliability, objectivity, and validity of the results collected in this qualitative descriptive study: (1) data triangulation was achieved by administering focus groups with several participants at various times in Consuelo and La Romana, (2) investigator triangulation was achieved by correlating the findings from multiple researchers in the study to reach consensus, and (3) theory triangulation was achieved by using and correlating multiple theoretical strategies in the form of the mixed behavioral theory frameworks of the ETAM and the IMB model [45,47-49].

Figure 1. Combined conceptual model: extended technology acceptance model (ETAM) and information-motivation-behavioral skills model (IMB).



Applying relevant behavioral theories to an mHealth intervention is important because it can lead to well-developed strategies for health behavior change and health promotion [50,51]. They can also increase the effectiveness of digital tools and promote a receptive environment for their use [51]. For these reasons, we chose to ground our intervention with behavioral theories that addressed both our targeted behavior of EBF for up to 6 months and acceptance of digital technology. The IMB model was initially developed to promote HIV prevention interventions in inner-city minority settings [52]. The model supports the hypothesis that to initiate and maintain a desired behavior, adherence-related information and motivation must be provided, along with appropriate tools to maintain the behavior [42,52]. In previous research, the application of the IMB model has shown great promise in developing effective EBF promotion interventions in global settings [53,54]. A common model used to understand clinical staff and patients' mHealth adoption is the technology acceptance model (TAM) [55]. Although the TAM has been a rigorously tested model in predicting user acceptance of an innovation, some have raised the need for the model to be extended and incorporated with further constructs to enhance its explanation and prediction of acceptance behavior [55,56]. Therefore, our study used an extended TAM that incorporates the TAM with the theory of planned behavior [41]. In addition to the original constructs of *perceived usefulness* and *perceived ease of use*, a trust-related construct (*perceived credibility*) and 2 resource-related constructs (*perceived self-efficacy* and *perceived cost*) are incorporated [41] to better predict caregiver and health promoter intention to use mobile phones for health information seeking.

Results

Overview

We conducted 6 FGDs consisting of (1) 7 health promoters from NPS, (2) 5 health promoters from CFLR, (3) 2 caregivers from MAMI, (4) 7 caregivers from CFLR, (5) 8 caregivers from MAMI, and (6) 6 caregivers from NPS. Demographics of the 35 participants are summarized in Table 1.

Table 1. Characteristics of focus group discussion participants.

Characteristics	Caregiver (n=23), n (%)	Health promoter (n=12), n (%)	Total (N=35), n (%)
Female participants	23 (66)	12 (34)	35 (100)
Age (years)			
12-17	6 (26)	0 (0)	6 (17)
18-25	9 (39)	1 (8)	10 (29)
26-34	6 (26)	4 (33)	10 (29)
35-54	1 (4)	7 (58)	8 (23)
No answer	1 (4)	0 (0)	1 (3)
Clinical site of recruitment			
Niños Primeros en Salud, Consuelo, rural	6 (26)	7 (58)	13 (37)
Clínica de Familia La Romana, La Romana, urban	7 (30)	5 (42)	12 (34)
Módulo de Adolescentes Materno Infantil, La Romana, urban	10 (44)	0 (0)	10 (29)
Highest educational level achieved			
Completed middle school	9 (39)	1 (8)	10 (29)
Completed high school or technical trade school	7 (30)	6 (50)	13 (37)
Currently at university	3 (13)	4 (33)	7 (20)
Completed university	4 (17)	1 (8)	5 (14)
Employment status			
Unemployed	19 (83)	7 (58)	26 (74)
Employed[a]	4 (17)	5 (42)	9 (26)

[a] Receives a salary for full-time work.

Demographic Characteristics

All participants were female. Each of the 3 participating sites accounted for a similar number of participants, with approximately one-third of the total from each site. Thus, the majority were from La Romana (22/35, 63%). A total of 12 participants were health promoters in their respective community, and 23 participants were mothers of children aged ≤5 years currently receiving services at either NPS, CFLR, or MAMI. The major demographic differences between caregivers and health promoters were age, education level, and employment. Notably, caregivers were younger (15/23, 65% were aged <26 years), had less formal education, and had a higher percentage of unemployment (19/23, 83% vs 7/12, 58%) compared with health promoters.

Participants' Use of ICT and Sources of Health Information

On the basis of a brief survey conducted before each FGD, all participants (N=35) reported having a cellular phone, of whom 29 (83%) reported having a smartphone. Participants obtained health information from the internet, physicians, health clinics, family and friends, health promoters, and TV.

Perceptions and Attitudes Toward mHealth

Most caregivers initially commented that they use ICT regularly to access health information. In the course of our FGDs, several factors influencing caregivers' use of mobile phones regarding their child's health emerged (Table 2). Prominent themes included ways caregivers use ICT, access limitations, perceived credibility of sources, perceived usefulness, cost, and privacy.

Caregivers utilized ICT in several ways. For example, some used ICT to access the internet to further research a diagnosis or medical terminology used by their doctor when they did not have enough time during their visit to ask. Some used mHealth to verify, confirm, or compare information received from different sources, including their family members and doctors. Others read or found health information using ICT and confirmed this information with a health professional to verify its validity or falsehood. Cumulatively, this health information–seeking behavior added further evidence to a major determining factor for caregivers' use of a potential mHealth intervention: perceived credibility of source. Caregivers consistently expressed the importance of having information in the mHealth tool that was validated by credible sources, such as doctors, nurses, and other trained health professionals.

Table 2. Perceptions and attitudes toward mobile health from focus group discussions.

Model constructs	Example excerpts
Perceptions and attitudes toward general health information	
Health information sources	• "I have a smartphone by which I can research on Google and YouTube about medication, about how to use them, about breastfeeding too. I inform myself by this form of communication: a smartphone." (NPS[a] health promoter, rural setting) • "There is a webpage that I used when I was pregnant. And there is another page that I follow, called: 'Lactating Mothers'. It informs you about the development of your baby, growing up, and all of the different things that happen." (MAMI[b] mother, urban setting)
Health information source considered most trustworthy	• "Directly with doctors, because you can find so many things on the internet and you don't know which ones are real. I directly call the doctor or I go to clinic." (CFLR[c] mother, urban setting)
Health information–seeking behavior	• "Sometimes the doctor can give a diagnosis or use medical terminology that we don't understand very well and, because of time, we don't ask the doctor. But we search on the internet. We search and we get all the information in layman's terms. The internet is really helpful." (CFLR health promoter, urban setting) • "Apart from the doctor, for your own knowledge, it's important to know what other sources say and also to search information on your own. To investigate and to have the opportunity to look for information and to learn." (NPS mother, rural setting) • "People that lived through the process like my mother and my mother-in-law. People who have previous knowledge about motherhood. And for something rare, I call the pediatrician." (CFLR mother, urban setting)
Facilitators and barriers to mobile health use for child health	
Perceived credibility of source	• "Sometimes we get confused, because a person comes and says something and then another one comes with another explanation. So it's better to look for people like promoters, psychologists, or doctors... It's better to ask them. They are trained people. Because sometimes people upload things and share information, but you get confused; then you ask yourself: Is it true or not?" (NPS health promoter, rural setting) • "It's not so bad. It has its pros and cons. What we have to do when we get information on the internet is to confirm it with the pediatrician. There is a lot of good information on the internet and many times we build on what we know and gain knowledge. And it's important." (CFLR mother, urban setting)
Perceived usefulness	• "Creating this app is a good way to give orientation about breastfeeding. Every mother can have it on her cellphone, because almost all mothers put more attention to their phone than to talks. Having the information on their phone, in order to have everything there, is a good idea. So they have the app and have access to the information." (NPS health promoter, rural setting) • "For me it's quite useful, because many people don't constantly remember things. Having a reminder of everything: vaccines, medicines, is very important. Because there are vaccines that if you don't get them in time, can cause harm to the child." (MAMI mother, adolescent, urban setting)
Perceived ease of use	• "I feel very comfortable, because it offers you the information instantly. When you want to know something and there is no one nearby you can ask; for example if the pediatrician is occupied or the doctor is receiving another patient and he cannot answer you in that moment. Then you have the information there, immediately." (CFLR mother, urban setting)
Barriers to ease of use	• "There can be problems with it. Because there are people that can't use technology well. There is good information, but some people don't know how to use it." (NPS mother, rural setting)
Perceived self-efficacy	• "[I feel] very comfortable because [technology] does not have time limits. I feel that I'm not bothering anybody. And I can easily dedicate time to it and I can easily find what I'm looking for." (CFLR mother, urban setting)
Perceived cost	• "Well, it's not so easy, because to obtain a mobile phone you have to pay monthly and it's not cheap. And you don't have money to pay every month. Sometimes they cut off the service and you cannot communicate; nothing. You can make calls but without internet you can't do anything." (NPS mother, rural setting)
Perceived loss of privacy	• "I think I would not [use an application asking for private information]. But I have Facebook and Facebook asks for your name and telephone number." (NPS mother, rural setting)

[a] NPS: Niños Primeros en Salud.

[b] MAMI: Módulo de Adolescentes Materno Infantil.

[c] CFLR: Clínica de Familia La Romana.

Perceived usefulness was another influencing factor for mHealth use, which was described among participants. Some caregivers described the usefulness of an mHealth tool both in terms of what they had encountered and what they wish were available.

Desirable characteristics and capabilities include quick and ready access to information, the ability to send reminders for important necessities such as vaccines and medications, and helpfulness with decision-making regarding their child's health. Several health promoters also explicitly mentioned how an mHealth tool would be especially useful to them during their home visits and provide them with an educational resource to share with their clients and families. Other factors identified among caregivers include perceived ease of use and perceived self-efficacy.

Some barriers to mHealth use among caregivers included perceived cost and perceived loss of privacy related to use. For example, many caregivers mentioned the difficulty of maintaining monthly internet service due to cost. If there were an additional cost of the mHealth tool, most mentioned they would not pay for it. However, some argued that if the mHealth tool seemed to add value to their lives, they would pay for it. When asked how they felt about sharing private information through the mHealth intervention, many expressed concerns about privacy and indicated that they would potentially input false personal information into a nonsecure ICT to maintain their privacy.

Perceptions and Attitudes Toward Breastfeeding and Influencing Factors

Participants observed and shared various factors that influenced their breastfeeding practices, which could be relevant to the development of an mHealth EBF promotion tool (Table 3). Most participants were aware of the benefits of breastfeeding for both their children and themselves, and some participants mentioned additional benefits such as economic savings and environmental benefits (eg, less waste production and reduced water consumption with no need for bottles and formula). Most participants were aware of the recommended time to initiate breastfeeding and the recommended duration of EBF. Change in knowledge was mentioned across the different focus groups as a major factor important to promoting breastfeeding. Participants proposed that this could be achieved through support or information from experienced family members or health care workers and through dispelling myths shared in the community.

Despite their knowledge of the benefits of EBF and intentions to exclusively breastfeed, detailed probing revealed that supplementing with water or formula in the first 6 months of life is common. Mothers provided reasons that included urging from the infant's grandmother to supplement, returning back to work, feelings that the baby was still hungry or that breastmilk production was inadequate, and previous experience with another child. Several mothers from the adolescent clinic (MAMI) also mentioned that their infant's grandmothers offered their babies beans, coffee, and other foods besides breastmilk as the initial food when their child was born.

Many mothers described their specific memories about breastfeeding, some reporting their difficulties and others sharing their positive experiences. Some shared challenges related to breastmilk production, physical pain, newborn refusal to latch, and preference to give formula. Other mothers, who shared positive experiences with breastfeeding, mentioned a feeling of having a stronger bond with their infant, health benefits to their infant (such as falling ill less frequently or seeing their rapid growth), and observing benefits for themselves (such as relief from breast engorgement or feeling thinner).

Table 3. Perceptions and attitudes toward breastfeeding from focus group discussions.

Model constructs	Example excerpts
Initial feeding practices	• "Yes, my mom gave him beans." "My mom gave coffee to him." "Enfamil[a], because I couldn't endure the pain of my breasts. They hurt a lot." (MAMI[b] mothers, adolescents, urban clinic) • "When my son was born, I immediately placed him on the breast and I continue to breastfeed him." (NPS[c] health promoter, rural clinic) • "At first I breastfed her, but she didn't like it. It seemed it was salty and I didn't insist. I bought her formula." (CFLR[d] health promoter, urban clinic) • "Well I practiced exclusive breastfeeding with my baby. Sometimes a little water, until 6 months, when I began to work." (CFLR mother, urban setting)
Facilitators and barriers to breastfeeding	
Information about breastfeeding	
Benefits of breastfeeding	• "Breastfeeding is very good, because the baby receives all the nutrients. But it's also very healthy for the baby and the mother, because doctors say that breastfeeding mothers have less probability to develop cancer. Babies grow up healthy, they don't get sick as often and it's very important." (CFLR health promoter, urban setting) • "Breastfeeding has a lot of benefits. The child socializes with their mother. You save money. You don't have to bring anything, because the mother is already carrying her child's food. It is good for the environment. I have a benefit, the child has a benefit, the environment has a benefit. Everybody benefits." (NPS health promoter, rural setting)
Myths surrounding breastfeeding	• "...There are breastfeeding mothers who are giving water apart from breastmilk, to the baby... It's important to explain to them...the baby doesn't need additional water, because it's in the milk." (CFLR health promoter, urban setting) • "I think that people believe one of the biggest inconveniences [of breastfeeding] is the myth that they will get very skinny and that the breasts are going to sag." (NPS health promoter, rural setting)
Change in knowledge	• "Well, for me, there is the challenge with my next child to practice exclusive breastfeeding, because my mom always told me to give breastmilk in addition to the formula, but nobody ever told me to breastfeed exclusively." (CFLR mother, urban setting)
Motivation to breastfeed	
Personal attitudes	• "Breastfeeding suits me and it suits the child. It's convenient for me, because while breastfeeding he becomes better acquainted with me. If he feels fussy or anxious, I begin to breastfeed him and he immediately calms down, because he knows that I stay with him. Because, since the child was in the mother's womb, his best friend is the mother's heart." (NPS health promoter, rural setting) • "It's also very good for us, women, because we get skinny (laugh). For this reason I breastfeed. You believe that it's because I like to give it, but no. It's to get skinny. Look at this belly!" (MAMI mother, adolescent, urban setting)
Support received	• "As I was a first time mother, my baby's grandmother urged me, because I didn't want [to breastfeed]. I was engorged. She said 'Give her breast!' and the milk finally letdown. She told me 'Give her breast! It helps her grow.' And then, with the second one, nobody had to tell me anything, because I already knew, because of what I had experienced with the first one." (NPS mother, rural setting)
Support desired	• "There are partners who believe that taking care of the baby is the obligation just of the mother. So there are fathers not supporting the mother in taking care of the baby. And I think it's work of 50% father and 50% mother." (CFLR health promoter, urban setting) • "It would be a good, an excellent idea [to have an application for breastfeeding], because right now, there are a lot of pregnant teenagers and they have no information about breastfeeding, about the consequences of breastfeeding or not breastfeeding." (NPS health promoter, rural setting)
Skills and experience with breastfeeding	
Perceived self-efficacy to breastfeed	• "At first, I felt a lot of pain; and then I got used to it and the nipples let down... I spoke with her and I carried her. She was tiny and I spoke with her and I got used to it. I loved giving my baby breast at a walking pace." (MAMI mother, adolescent, urban)

Model constructs	Example excerpts
Successful breastfeeding experience	• “I had a very pleasant experience. Because I had to breastfeed twins, I will never forget. It was something very new for me, because breastfeeding two children at the same time is a bit difficult, but I learned that breastfeeding is important, because it helps our children’s nutrition and that the development of our children depends on it, as they grow. Because if we breastfeed, they will have the antibodies they need for any disease. I learned that it is important to breastfeed.” (NPS health promoter, rural setting) • “Breastfeeding the baby is very good. I breastfed mine for 1 year and 10 months. And this baby never got sick, thank God.” (CFLR mother, urban setting)
Unsuccessful breastfeeding experience	• “My experiences [with breastfeeding] were not very long. I have two children. A boy that is 7 years old and a girl that is 6 months. The boy breastfed until he was 3 months. I tried to put him on the bottle [with expressed breastmilk], but he didn’t want it anymore and me neither. The girl wanted to stop after 2 months. I pumped breastmilk and I gave it to her, but she didn’t want it anymore.” (NPS mother, rural setting) • “When I saw the blood coming out of my breasts, I was scared. My nipple was cut by so much breastfeeding. I had cuts and I said: ‘Oh my God! I have to stop it! I have to save myself from that!’” (CFLR health promoter, urban setting)

[a] Brand of infant formula.

[b] MAMI: Módulo de Adolescentes Materno Infantil.

[c] NPS: Niños Primeros en Salud.

[d] CFLR: Clínica de Familia La Romana.

Desired Features for a Potential mHealth Intervention to Address EBF

In addition to sharing their perceptions and attitudes toward mHealth in general, participants provided their recommendations for important features to include in a potential mHealth intervention to promote EBF (Table 4).

A frequently mentioned recommendation on how to introduce mHealth for EBF support and promotion was having the ICT cover other topics related to their child’s health in addition to breastfeeding, such as growth and development, vaccines, prenatal and postnatal health, and common ailments. Other factors perceived to be important included (1) using an app that would be easily accessible on a smartphone with remote access due to commonly inconsistent internet service; (2) having an interactive component, whether through video call or face-to-face consultation; and (3) using simple, educational, and motivational messaging with video and images. Others suggested using *myth-busting* messages. Health promoters and pregnant women were also identified as specific groups that could especially benefit from this mHealth tool. For example, health promoters suggested having a platform to be used as an educational tool for home visits. Participants also proposed targeting pregnant women who could have access to this information while preparing to give birth and raise a child.

Table 4. Desired features of a potential mobile health intervention: major themes from focus group discussions.

Major themes	Example excerpts
Message content based on specific topics	• "To speak about hygiene, about fever, about the most common diseases, about infections he can have, about influenza which is very common, and growth." "I would like information about nutrition and home remedies for children." (MAMI[a] mothers, adolescents, urban setting) • "A reminder for vaccines and, if possible, the information about which vaccines the baby should get would be very important." "I'm not sure it's good to fill the application with too much information. But maybe you can put information about pregnancy... It would be very useful." (CFLR[b] health promoters, urban setting)
Timing of information	• "For me, it's important to get it daily, not flooding people with messages, but with one paragraph specifying something on the theme. In the notification, you want to know about this topic, or in a video, specifying all you have to do. For example, if they speak about how to feed the baby after [6 months of] breastfeeding. It's important to specify, more or less, the food that you can give to him, how and the quantity." (CFLR mother, urban setting)
Preferred method of delivering information	• "An application would be good because I can have it on the phone, so whenever I need information, I go to the application directly. I suppose the application will contain the videos and the texts that people are looking for. So, I prefer an application." (NPS[c] health promoter, rural setting) • "I also like face-to-face. I like it, because when you speak with the other person, you can see how they receive the message, and you can say: 'Did you understand? Repeat it!' You can understand better face-to-face. Videos too. Through videos you can live what you are seeing. So, I like both, but mainly face-to-face." (CFLR health promoter, urban setting)
Message intent	• "Motivational. 'Care for your baby like you care for yourself!'" (MAMI mother, adolescent, urban setting) • "I recommend informing about breastfeeding, because there are many myths that one believes, because I have mine too. The pediatrician, health staff, application or a webpage can dispel these myths in order to give better benefits to children." (CFLR mother, urban setting)
Target audience or target strategy for an eHealth tool	• "[An] application is very good, because we are [health] promoters. We go to a mother's house to do a home visit and through the app we can show her the information. A lot of them don't pay much attention to what we say sometimes. So I can show them that through the app, she can find all the information about vaccines, breastfeeding… and I can show it to my family and to the entire community." (NPS health promoter, rural setting) • "In this app, I want to find themes related to breastfeeding; about pregnancy, how to be prepared; because a mother can access it and she can find everything related to her and to her baby... So that when a mother gives birth, she knows how to nurse him, she knows the benefits of breastfeeding and she knows what happens with formula. Sometimes we can say to a mother that breastfeeding is the best, but sometimes they don't trust us. But if they have information, they can say: 'Wow, it's true. Look! Here it tells me!' Sometimes they want evidence. If we have this app, it's much better." (NPS health promoter, rural setting)
Other features	
Telemedicine	• "If you are at home and the baby has a problem, you can start a video call and you can ask at that moment. ['The trained professional'] can tell you what to do, before taking the baby to the doctor." (NPS mother, rural setting)
Remote access	• "Because it may be that I won't have internet on my phone and that I can't search something on the application. If I don't have money to activate service, it would be good if it does not need internet connection." (NPS mother, rural setting)
Myth busting	• "It would be good to scientifically define the origins of the myths and discredit them or not." (CFLR health promoter, urban setting)

[a] MAMI: Módulo de Adolescentes Materno Infantil.

[b] CFLR: Clínica de Familia La Romana.

[c] NPS: Niños Primeros en Salud.

Discussion

Principal Findings

Mobile phones are increasingly common in the Dominican Republic, where, according to the World Bank, there were 84 mobile cellular phone subscriptions per 100 people in 2018 [57]. In addition, smartphone use in this setting is increasing rapidly; a 2019 survey found that 61% of the Dominican population owned a smartphone compared with 51% in 2017 [58]. This rapid expansion of access to mobile technology creates an opportunity to develop health-related interventions to meet the needs of rural and urban communities across the Dominican Republic. This study provides novel insights into community and caregiver perspectives of a potential mHealth intervention to promote EBF for women with children receiving care at multiple clinical sites in the Dominican Republic. This study also highlights numerous aspects of the content and service delivery model that may affect users' acceptance and impact of the intervention. By identifying caregiver and health promoter opinions on a potential mHealth tool using behavior theory models, the results can inform effective future mHealth intervention design.

Effective mHealth research should aim to provide a richer understanding about the nature of the cultural factors [59] that shape the adoption and success of these new technologies. This study aimed to address the gap in mHealth research related to user acceptability and the development of theory-based interventions. There is a need for more mHealth interventions grounded in behavior change theory [28,59] that explore the psychological, cognitive, and behavioral dimensions of maternal and child health, which served as the foundation of our design.

We do not have similar previous studies for comparisons, as this study is, to our knowledge, the first study of its kind in the Dominican Republic. However, other studies have assessed the feasibility and acceptability of mHealth apps aimed at improving breastfeeding in other countries [27-30]. For example, in Saudi Arabia, more mothers expressed their intention to practice EBF after receiving mHealth-based education about EBF and early breastfeeding initiation [27]. An Australian study reported high ratings for an evidence-based breastfeeding app designed to provide men with social support and information to enhance the help they can offer their breastfeeding partners [28]. A Thai study demonstrated the potential for an mHealth app to be a useful self-management tool for breastfeeding mothers [29]. In the United States, researchers at the University of Missouri found that stakeholder and user engagement indicated that mHealth has the potential to be a useful strategy for providing breastfeeding support to mothers [30]. These studies, combined with the findings of our study, indicate the potential positive impact an effectively designed stakeholder-informed mHealth tool can have in promoting EBF.

Mobile phones provide an opportunity to improve health behaviors, as evidenced by caregivers in this study who mentioned that their intention to breastfeed may have been enhanced if they had better access to trusted information about EBF from an mHealth app. According to the 2011 World Health Organization report on mHealth, mobile phones provide a new communication channel for health promotion and community mobilization [60]. Multiple studies have shown promising results of using mobile phones and text messaging to improve nutrition [27-30,61,62]. Multiple systematic reviews have evaluated the impact of mHealth interventions on maternal and child health in LMICs [59,63-67]. These reviews have noted that although a handful of interventions have shown some promise in improving health outcomes compared with routine care, most studies lack high methodological quality, such as theory-based design, standardization of content, and validated outcome measurements [59,63-67]. This observation is important not only during the mHealth design phase but also in the future evaluation of the resulting mHealth intervention.

Applying Findings to Future Intervention Design

Our findings provide an additional context to the low EBF rate in this population that can inform future breastfeeding interventions. On the basis of participant responses with probing, mixed feeding (a combination of breastmilk and formula) appears to be common. The reasons given for this practice, such as returning back to work, feeling the baby is still hungry, and feeling like breastmilk production is inadequate, have also been mentioned in previous studies [68-70]. Thus, this work confirms that it will be important to address factors associated with mixed feeding in a future mHealth intervention aimed toward this community and others with similar practices.

Our findings suggest that caregivers and health promoters in this setting prefer to utilize a low- to no-cost health app that is easily accessible on mobile phones, regardless of internet service. This supports previous research examining trends in mHealth in LMICs [71]. Participants also generally preferred to have access to a trustworthy trained individual or specialist to navigate and promote EBF. In this setting, it is culturally accepted, and many times sought after, to have face-to-face interactions with trained professionals to obtain health education and consultation. As suggested by participants, this desired component can be applied to an mHealth intervention by either adding a video call feature or discussion forum component to the intervention. Participants also suggested that during health visits, physicians, nurses, or health promoters can use the mHealth tool to explain standardized health information and provide access to the mHealth tool for caregivers to use beyond the encounter. Similar findings have been reflected in previous research in the development and assessment of mHealth interventions in other countries, including India and Germany [12,72,73].

Perceived loss of privacy is an important barrier to mHealth use mentioned by participants, which has also been described in other studies [74,75]. As illustrated in the quotes in Table 2, there are conflicting attitudes toward providing private information in mobile apps. Although some participants mentioned that they would not use an app that required private information, some reported that they would input false personal data to access the app. Regardless of privacy concerns, popular apps such as Facebook were still used among our participants, which may indicate that functionality and convenience may take precedence over privacy concerns. Further research is needed to address concerns regarding privacy and security in future mHealth apps and to explore if it is necessary to be specifically customized for different purposes or users.

Caregivers in our study expressed that although an mHealth tool to promote EBF would be useful, it would be desirable if the tool could provide additional information and self-management support for other maternal and child health topics, such as growth and development, vaccines, prenatal and postnatal health, and common childhood illnesses. This corresponds with previous literature in which caregivers described mobile apps to be better suited for more broad topics that would be accessed more frequently or to meet a repeated, unique need to be worth the significant space and data on their devices [76]. In addition, in considering the design of an impactful mHealth tool that is highly valued and frequently used by parents, a previous systematic review recommended combining educational elements with troubleshooting support [71]. Future intervention designers should take these considerations into account to provide optimum benefit for the intended target population.

Strengths

A strength of this study is inherent in its design and employment of several categories of triangulation (data, investigator, and theory) to enhance the reliability, objectivity, and validity of the results collected [45,47-49]. In particular, data triangulation allowed for the collection of different perspectives from female caregivers and health promoters of various ages living in both rural and urban settings in the Dominican Republic. There are several examples that illustrate triangulation in our data. As seen in Table 3, there is an overlap between a myth about breastfeeding and motivation for breastfeeding. A rural health promoter mentions that “one of the biggest inconveniences [of breastfeeding] is the myth that [mothers] will get very skinny,” whereas later, an urban caregiver describes how getting skinny was a motivation for her to breastfeed. The second example of triangulation appears when a rural health promoter mentions that she would like support aimed toward pregnant teenagers because they have “no information about breastfeeding” (Table 3). However, an urban teenage mother mentions a specific website called *Lactating Mothers*, which she uses to seek health information regarding her child and breastfeeding (Table 2). These findings form a strong evidence base and source of various perspectives from which mHealth interventions that seek to improve EBF in the Dominican Republic and other similar settings can be designed.

Given the extensive description of the methodology and design of our study, researchers interested in conducting similar work can better understand how our findings might apply or relate to their target population [77]. This study integrates the perspectives of stakeholders (caregivers and health promoters) throughout the design process. Formative research with stakeholder involvement is foundational to delivering effective maternal and child health educational interventions and facilitating a more sustainable and broader dissemination [76]. Furthermore, within the global health community, we must look across specific content areas toward the broader themes emerging within the literature on technology-based interventions. Consistent with previous studies, this serves as a call to action to pair formative research with strong evidence-based design, combining messaging type and content with optimum technology platforms to effectively improve health outcomes [17,18,28,59,63-67,78].

Limitations

Despite these strengths, there are some limitations that should be considered. There is an inherent selection bias owing to our recruitment strategy, which involved approaching potential participants in the clinical site waiting areas. One might argue that women living in local communities, who are not actively seeking primary care services, may have the greatest need for breastfeeding education and guidance. This selection bias might have been avoided if we had sought help from the health promoters to identify women in the community who do not use primary care services. However, as free services are highly accepted, women not accessing these services are less representative of the population as a whole. Another limitation is that the FGD guide was not modified to elicit the unique perspectives of mothers in the older age groups or to address any contradictions seen in the data. There was a missed opportunity to further identify barriers to EBF, such as exploring reasons for mixed feeding practices among older mothers, or provide a direct context to the contradictions observed. Third, it must be mentioned that the principal investigator was also a staff pediatrician at 2 of the clinical sites (NPS and CFLR). Although she did not facilitate the FGD, she was present for notetaking and observing the groups in each session. Owing to this, participants may have modified some aspects of their responses toward breastfeeding with the awareness of being observed (Hawthorne effect) [79]. However, the fact that participants freely admitted to behaviors such as mixed feeding, which they likely knew to be contrary to the pediatricians’ recommendations, suggested that they felt free to express their true behaviors and feelings in the presence of a pediatrician.

Our study findings may not be generalizable to communities in the Dominican Republic where levels of employment are higher. On the basis of data from the World Bank, in 2019, the labor force participation rates (eg, percentage of people aged over 15 years who are employed or actively looking for work) were 51% female and 77% male [80], compared with 26% of our all-female study cohort. A unique distinction about the clinical sites in this study is that medical services are significantly subsidized for patients. For example, patients who qualify for NPS services have no fees for visits, laboratories, or medications. To be a patient at NPS, children must be aged ≤5 years and live in 1 of the 8 *barrios* (neighborhoods) served, which are the poorest in Consuelo. In addition, at CFLR, people living with HIV receive government-funded highly active antiretroviral therapy (HAART) free of charge. Laboratories and medications are offered at a significantly lower price than at other facilities in La Romana. This provides context as to how recruited participants are able to receive care despite high unemployment rates.

Conclusions

There is a high level of acceptance for ICT tools, particularly mHealth apps, for the promotion of breastfeeding and child health among caregivers in this setting. mHealth tools can contribute to increased breastfeeding self-efficacy, and hence, identifying the desirable features of such tools will create impactful interventions in both rural and urban settings in the Dominican Republic. Future mHealth interventions should be designed using formative research with stakeholder involvement. Ideally, the mHealth tool should implement the following features:

- minimize barriers to use, such as low cost and access without active internet service
- promote frequency of use by adding perceived value to caregivers, such as providing both educational and self-management content

- address the cultural needs and acceptability of users based on behavioral theory models.

In general, caregivers want to receive trusted and reliable information that is easily accessible through various formats, and they are interested in information beyond breastfeeding.

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Conflicts of Interest

None declared.

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Abbreviations

CFLR: Clínica de Familia La Romana
EBF: exclusive breastfeeding
ETAM: extended technology acceptance model
FGD: focus group discussion
ICT: information and communications technology
IMB: information-motivation-behavioral skills
LMICs: low- and middle-income countries
MAMI: Módulo de Adolescentes Materno Infantil
mHealth: mobile health
NPS: Niños Primeros en Salud
TAM: technology acceptance model

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