Towards Better Transitions for Children with Diabetes: User Experiences on a Mobile Health App

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Abstract

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Children with Type 1 Diabetes (T1D) are required to manage their illness to alleviate further long-term complications. Although children are expected to engage in appropriate self-management activities once they become older, many of the children remain passive actors in managing their condition. Due to the lack of knowledge and skills, as well as changes in parent-child relationships, children demonstrate low self-care adherence. Consequently, parents also face difficulties in defining their role in long-term care. This study, part of a larger study, comprised of three phases: mobile app development, prototype feasibility testing, and usability testing with child-parent dyads users. As part of the third phase, this study used qualitative interviews with 24 child-parent dyads to understand the existing facilitators and barriers in using the app. Our findings suggest that users found that the app reminded them to track their blood glucose (BG) values and facilitated child-parent communication in a user-friendly manner. By capturing the emerging themes in adopting the app from the children's perspective, we will iteratively refine the app to better suit the users' requirements.

Keywords

family communication; parent-child interaction; participatory design; mHealth; diabetes

ACM Classification Keywords

CCS → Human-centered computing → Interaction design → Interaction design process and methods → User centered design

Figure 1: A mobile application, *MyT1D Hero* was designed in our larger study

Introduction

More than three-quarters of people with Type 1 Diabetes (T1D) are diagnosed when they are younger than 18 [13]. Family caregivers, generally parents, often assist their children to manage the complex management of the disease [9]. As young patients become older, they are asked to start engaging in more self-management activities, such as regular blood glucose (BG) monitoring and calculating insulin based on BG results. As the management of the disease affects everyday life, appropriate support and tailored coping strategies are necessary to achieve independent self-management. However, the current diabetes care environment rarely addresses the importance of including both parties, children and parents, in the development of interventions [5]. Lack of stepwise transitions not only negatively impacts family relationships as family caregivers often struggle to relinquish control over management, but also the child's self-care which often leads to serious long-term complications including comas, seizures, and even death [2]. One way that has been found to help are mobile health (mHealth) interventions [1]. Therefore, a diabetes management app was developed to test its impact in improving the transition, followed by a usability test of the app with 48 participants: 24 pairs of children who are undergoing T1D and their primary caregivers. In this paper, we present barriers and facilitators that were identified from semi-structured interviews with children and caregivers. Future directions are also discussed.

Background and Related Study

The advent of new information and communication technologies (ICT) has promising impacts on the treatment of chronic diseases [8]. Recent studies in HCI and healthcare domain highlight the scope and the benefits of available technology-mediated interventions designed for children and their families specifically in health [13]. These interventions range from family-centered health management [11] to health information delivery [7]. Studies have revealed that shared responsibility and support among family members have positive impacts on illness management [10]. Despite the recent studies, there has been limited investigation of the possible directions in facilitating communication between children with chronic conditions and their caregivers that seek to engage children as active participants for their symptom management. As children have not developed enough cognitively, caregivers must often take manage the illness on behalf of their children [12]. This can result in poor self-care adherence and has proved to be burdensome over time as children become more responsible for care. Given the benefits that technology provides in the healthcare environment, mobile health (mHealth) applications have the potential to alleviate some of these barriers [1]. In our larger study, we designed an Android application, *MyT1D Hero*, which aims to support the children's initial transition to independent diabetes management [5,6] (See Figure 1).

Data Collection

All study participants were recruited from a diabetes support group in Michigan, United States. After the participants were provided with information regarding the app and had used it for 3 months, we invited them for the semi-structured phone interviews. Each phone interview lasted approximately 20 minutes and all interviews included both children and their parents, separately.

Interview questions were designed to capture the user experiences with the app for their diabetes management. We focused on users' general first impressions and frequency of app usage, how the app impacted parent-children communication with regard to diabetes management, barriers of incorporating the app in their activities of daily life, and possible design implications that would potentially engage other users in the future. All interviews were audio recorded and professionally transcribed verbatim. Personal identification and information was removed to protect privacy. Ethical approval was obtained from the University Institutional Review Board (IRB number 17-211M). We obtained written consent from adults and assent from children.

Study Participants

The study participants include 24 children between 10 and 15 years old with T1D and their mothers. Fifteen of the children were between 11–13 years old, and 13 children had been diagnosed for five or more years. Among parents, 18 were the biological mothers, and 11 were between the ages of 35–44 years.

The design concept of the app is to promote responsible diabetes management among children and increase their independence, while helping parents stay engaged and encourage their children in alleviating the common challenges to T1D management (i.e., low adherence to their treatment regimen) throughout the transition period. Using the separate apps, parents and children are linked remotely and work together on diabetes management. When children record their health information, such as BG, the app allows their parents to obtain this information in a seamless and unobtrusive manner. The app also contains pre-programmed messages that users can easily send to each other and reminder cues aimed to improve close self-monitoring. These features are tied to the app's visualized reward system in which children can customize their own superhero character when they receive the points by entering in their BG into the app and messaging with their parent (See Figure 4). Study results on the app development and initial feasibility test outcomes have been reported previously [5,6]. The current study employed qualitative interviews with 24 child-parent dyads to understand the existing facilitators and barriers in using the app.

Overall Results

Overall, the study participants reported that the app was helpful, allowing them to conveniently track their BG values and generate a short and simple message (See Figure 3). The child participants expressed their overall reactions to the app with comments such as: "I think using the app is a really good idea. It makes it a lot easier to communicate between me and my mom when we are eating at the house or even when we are—stuff like that. I would—if my blood sugar seems like really high or my blood sugar is low, and I need to know what my mom wants me to do, it's just going through my regular messenger and stuff like that, I can talk to her through there (Child (C) 18)." Participants also mentioned a sense of connection which was evoked by the app use even when they were not together. It allowed children and their parents to know their BG level without spending time and efforts, and it could tell whether the number was within the recommended range. One mother mentioned her greatest perceived benefit of the app: "The best thing, I think, is being able to see his blood sugars when he isn't with me. He could put things in and then I could see them even if he wasn't with me directly (Parent (P) 12)." Through our qualitative data analysis, we identified four primary themes of children's and parents' experience. Emerging issues we identified here will be applied to our next version of the app design and future design opportunities.

Findings and Future Directions

Need of integrating the app naturally into children's school

A majority of participants pointed out that the app is particularly useful when children and parents are not together. Being able to know the children's BG results when they are at school helped users

Data Analysis

Emerging issues captured from the interviews were regularly discussed among the study team members in weekly group meetings. After the study team members had repeatedly reviewed and discussed the interview transcripts, an initial set of open codes were devised that were further refined using affinity clustering [4] to identify the relationships between the clusters (See Figure 2). Multiple iterations of affinity clustering and discussions allowed the elimination of discrepancies by adding and integrating codes. Each interview script was coded using the refined codebook, and we subsequently narrowed our findings into four main focuses.

Figure 2: Affinity clustering to identify the relationships between the captured themes

to reduce burden on both parties. One participant reported that her child's app usage happened mostly at school: "Monday through Friday, he used it during school hours. He uses it about three times a day during the school day. In the evenings and on weekends, we didn't use it because he was typically with his dad or myself (P11)." However, at the same time, regular monitoring of BG and communication with parents were challenged by many unexpected situations at school. These issues included school activities that happened out of their routine which hindered keeping BG monitoring as their natural routine, technical issues with wi-fi connections, and the school's phone regulation policy regarding students. A child reported barriers associated with technological issue which were out of her control: "At school during lunch and stuff where I would put it in, the internet at the school would not allow me to sign in to the phone itself and therefore, I couldn't use the app and the 4G was not working very well with it. (C12)" The other child expressed her frustrations on remembering to enter her BG information at school: "I started like getting scared when I was starting to bring it to school because I was scared that like I'd forget. I'm just like, oh my gosh. I forgot to do that. Sometimes I would forget to it, completely forget like all day and then at the end of the day I'm just like, oh wait. (C13)" This feedback allowed us to consider the necessity of understanding and capturing the children's daily routine in tracking their BG levels especially at school and incorporating identified issues.

Need to provide tailored support based on illness stages

Many parents mentioned that it would have been much more helpful if they had this app at the beginning of their T1D diagnosis. Because children and parents naturally develop their own coping strategies over time, they pointed out that the app would be particularly beneficial for people who just started establishing BG monitoring routine and seeking coping resources. At earlier stages when children first begin their long-term illness management, many children and parents have difficulties due to the unfamiliar medical requirements they have to meet, such as food intake tracking or BG value recording [2]. One parent provided her insight in using the app pointing out its potential to reduce parents' anxiety at early stages: "If we had had it [the app], maybe right after his diagnosis, we might have been more inclined to use it. Yeah, I think it could be helpful to families. Because when he was first diagnosed, and he was getting help with I think it could be helpful to families for sure. I think if his injections at school, I wouldn't always know what his sugar was. I mean I could check his meters, but I wouldn't always know right when that was happening, and that anxiety of the new diagnosis. If I had access to that, I think that would have been really nice to have (P19)." This led us to consider ways to maximize functions of the app targeting for children who needs more support than others. Given illness management is transactional, rather than a static, it would be necessary for our future version of the app to consider particular requirements at each stage of the illness and provide tailored support.

Figure 3: Pre-programmed messages that users can easily send to each other

Figure 4: Children can customize their own superhero character whenever they receive the points by reporting their blood sugar on time

Benefits of providing a calibrated mode of rewards

One of the most frequently occurring themes during the interview was the positive impressions on the reward system in the app (See Figure 4). As we introduced, the app provides a visualized reward component in which children can customize their own superhero character whenever they receive the points by reporting their blood sugar on time and communicate it to their parents. The child participants reported their motivations to receive rewards and were excited to see direct outcomes they made by meeting the app requirement: "I think it keeps you accountable for putting in the blood sugar, so you can see the direct results from that. It keeps you accountable for putting the blood sugar in (C27)." A number of participants had suggestions on making the app more engaging for use over a longer period of time. One participant wanted to have more options for decorating characters (i.e., more clothes or boots) and advanced functions: "I just wished it could add a little bit more onto it. The avatar could be part of a larger game that they could put into the app (C12)." Findings from the interview show that providing visual rewards has a positive impact on augmenting motivations and functions as an entertaining factor that possibly engage children in a long-term app use. This led us to consider having a participatory design workshop with our children user group. As a next step, we will collect user insights in a more visually-oriented manner and establish robust directions for the advances of the reward system.

Adopting peer support functions

Other participants interviewed expressed the necessity of having peer support components. For many families, it is difficult to find peer groups in their area (especially rural areas) to provide support and reduce feelings of isolation. A mother stated that her child has positive reactions toward other children who have T1D: "Anytime she sees another child who has had T1D, she's like, 'Ooh, it's like one of me, one of me.' And, you know, she'll talk to them if she has the chance and that's why I do think that that [adding a peer support component] would be a good idea (P18)." Interacting with peers impacts children's developmental process, especially during the adolescent stage. Children with chronic conditions often report having fewer friends, participating in less social activities, and feeling isolated as compared to their normal friends [3]. For example, a parent referred to her son as a "lone-boat" in his school, expressing her desire to have peers who have similar health conditions as her child. In our updated version of the app, we are planning to develop peer support functionalities, such as team competitions.

Conclusion

Our approach to include children with T1D as main participants captured the user perspectives that would allow us to establish the future directions of the app. The next steps of this study include having a participatory design workshop with children and generating a more concrete design idea based on the findings we present. With these efforts, the next version of the app would better meet children's

Limitations

Our study has several limitations that should be acknowledged.

First, the study participants reported the decreased frequency of the app usage after the first couple of weeks. In framing our usability study, we accounted for the differing levels of children and parents' app usage. Future studies should address how could we engage users over longer periods of time.

Second, the app was developed for the Android-based platform, and people who did not use an Android phone had to carry two phones to participate in our study. Also, there were some participants who utilized diabetes management apps that have similar functions as our intervention (i.e., Dexcom, mySugr app). These hinder measuring the direct effects of people who use multiple devices. Our future iterations will include an iOS platform.

Third, this study does not include the results from the technical errors that were reported from participants, such as unexpected shutdown and errors in reminders. However, we were able to resolve the technical issues noted by the participants.

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needs and further promote independent diabetes management for long-term self-care.

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