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Digital Support for Self-Management in Children with Diabetes: Understanding Their Needs and Developing a Design Concept

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Abstract. In this paper we present a study on the needs and requirements in a digital tool to support self-management in children and adolescents (0-18 years) with type 1 diabetes. The study was formally initiated by the Steno Diabetes Center North Jutland (SDCN), which wanted to develop a virtual universe that could support children and young people in coping with their disease. Through this study we interviewed the project manager from SDCN and the head of the family group in North Jutland. Furthermore, we observed a workshop involving health care professionals and learning specialists who were working with ideas for the virtual universe. We conducted two focus group interviews, one for children with type 1 diabetes and one for parents with diabetic children. The analysis of the data revealed very different ideas about what digital support is important for the self-management of this target group. Health care professionals focused on developing various learning materials using virtual reality or augmented reality, while the parents desired security and control and requested materials that could inform and educate people in their locale, such as school teachers, parents of their children's friends, etc. The children emphasized the importance of not being singled out and requested simple tools that could be used from their smartphones. They especially asked for tools that could help them manage their diabetes by themselves in a fast and effective way, e.g., making it easier to count carbohydrates and calculate their insulin intake. Based on the analysis, we developed suggestions for a design. The main lesson learned from this study was the importance of focusing on the *actual* users and their everyday lives in developing new tools, and not on technological possibilities.

Keywords. diabetes; app design; user research;

1. Introduction

In 2017, approximately 425 million adults (20-79 years) and more than 1,106,500 children lived with the chronic disease diabetes [1]. The most well-known types of diabetes are type 1 and type 2. Type 1 diabetes occurs when people cannot produce insulin themselves and type 2 diabetes occurs when people cannot use insulin to turn glucose into energy [1]. The study presented in this paper focuses on children diagnosed with type 1 diabetes [2].

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Diabetics have an increased risk of serious health issues and complications, including cardiovascular disease, blindness, kidney failure, and lower limb amputation [3]. It is therefore important that children and young adults learn to self-manage and take responsibility for their disease even at a young age. To help children and young adults manage their diabetes, the Steno Diabetes Center North Jutland (SDCN) wished to develop a digital concept that supports diabetic children and their families in their everyday life. When we began our cooperation with SDCN, the vision for the project was still in a very early state, but SDCN knew they wanted “something digital” and were interested in the idea of a virtual universe for the children. It was important that the digital device would support self-management and empowerment, that is, to maximize the self-care knowledge, skills, self-awareness, and sense of personal autonomy of patients and to enable them to take charge of their own care [4].

To understand the context of diabetes-related technology, we explored existing ICT apps and tools for diabetes on the market. We found several diabetes-related apps, but almost all the apps were made for monitoring diabetes. We found only one app, provided by the Danish Diabetes Association, that was developed to help children master and manage diabetes. Monitoring and mastering/managing are different types of help: monitoring focuses on keeping track of your numbers (insulin, blood glucose levels, etc.) while self-mastering also focuses on having the knowledge and competences to handle and manage the disease. The collaboration with SDCN led to a study on the needs and requirements for digital support to aid self-mastery for diabetic children, aged 10-18 years, in order to develop suggestions for a design.

2. Methods

For this study, we applied a user-centered approach [5] to understand the aims and needs of the stakeholders: the children, the parents, and the health care professionals.

We conducted an unstructured interview with the project manager from SDCN with the aim of understanding the thoughts and wishes regarding a virtual platform for children and teenagers and why this project was initiated. A few days after this interview, we participated in a SDCN workshop to inspire innovation in digital health for children and teenagers with type 1 diabetes. Doctors and nurses from Aalborg University Hospital worked with two digital learning specialists from a company called CadPeople and the project manager from SDCN. While observing this workshop, we conducted an unstructured non-participatory observation and took fieldnotes. After collecting data from health personnel and experts, we wanted to obtain the users' perspective. Therefore, we had a conversation with the chairman of the Danish Diabetes Association of Northern Jutland. Through our contact with the chairman, we arranged two separate focus-groups, one with 8 children, aged 9-13 years, and another with 7 parents. We prepared an interview guide for the children with questions that allowed us to focus on their experiences and feelings about being diagnosed with diabetes and dealing with the disease. We asked the parents questions about parenting a child with diabetes. As expected, the parents were able to reflect upon the questions, whereas the children needed help. Therefore, we chose to include the generative techniques inspired by Sanders and Stappers [6]. We used pictures in the form of different social activities to provoke reflection and help the participants to recall memories, make interpretations, explain feelings, and imagine future experiences.

Data from the interviews, observations, and focus groups were transcribed in order to for us code it and draw out the relevant knowledge from the study. The coding process was approached with an open mind; as a framework we followed Braun and Clark's six-step thematic coding [7]. This led to the identification of important themes that are presented in the findings below.

3. Findings

The identified themes represent the different issues and challenges that the children and their parents encounter on a daily basis, including "Practical challenges with diabetes," "Challenges when educating the network," "Lack of knowledge about the illness," "The balance between independence and childhood," and "Overprotective parents". We condensed the themes further and ended up with three main concerns that should be addressed in a digital tool that could support self-management. The first one is easy access to carbohydrate calculation, the next is easy access to relevant guides and information, and the third one is what to do in an emergency.

Besides these findings, it was also clear from our interview with the children that they wanted a solution that they could carry with them all the time. The children already have access to an app that counts carbohydrates, provided by the Danish Diabetes Association. But this app does not provide its users with sufficient options or a large enough database to support self-management. Inspired by this app, our aim was to come up with a digital solution that improves all aspects and functionalities, based on the identified themes and concerns from our analysis.

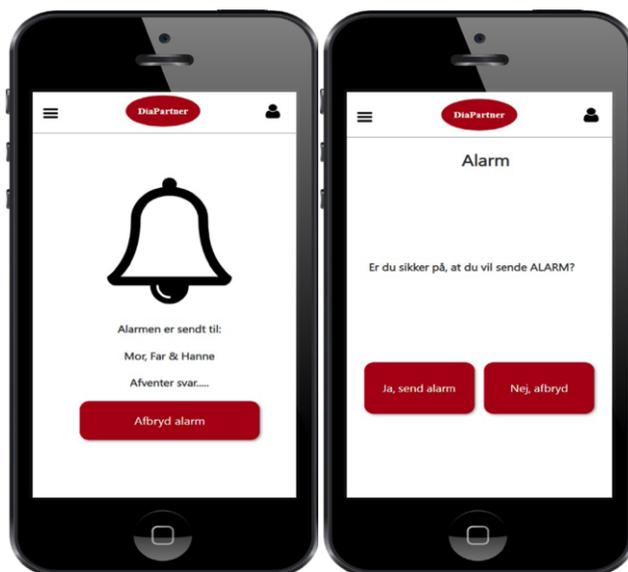
The current app is not easy or fast to use in counting carbohydrates. For example, the application should provide the users with a larger database of food and beverages that must be easy to navigate and the users must be able to select specific kinds of food and beverage as "favorites" (see Picture 1).



Picture 1. Show product and save as a "favorite"

Furthermore, the application had to inform and provide advice about type 1 diabetes, not only to enlighten its users (the children with diabetes), but also to provide the network with an easy and accessible way to learn about the disease. Thus, it was a main concern for the parents that e.g. school teachers, sports association leaders and others did not have the necessary knowledge about diabetes to take care of their child. Therefore, the child could not participate in social events like summer camps and sleepover parties. An important part of this issue is also a specific guide on how to handle a hypoglycemic incident

Another result of the data analysis showed that there is a need for a function that could help the children and their parents to feel more confident that they will get help quickly if needed, especially when the children are away from home. Therefore, we decided to incorporate an alarm. To do so, we had to include and activate the phone's GPS, which caused several ethical questions whether the purpose of the application is to support the children's self-management—not for the parents to be able to track them. Instead of activating the GPS all the time, we developed the ALARM function so the users (children with diabetes) could include three different emergency contacts. If the alarm is triggered, these contacts receive a message with the child's location (see Picture 2).



Picture 2. ALARM

In summary, the design proposals point to a relatively simple solution that particularly addresses the demands of children for easy access to carbohydrate calculations and the parents' requirements for security and access to relevant information for networks and friends.

4. Discussion

The analysis of the data from the health professionals, parents, and children revealed very different foci about what is important in digital support for children and adolescents

with type 1 diabetes. The workshop with health care professionals resulted in three design suggestions: a digital diabetes diary, an interactive understanding of diabetes, and the implementation of virtual reality to build bridges between parents and children. The parents' concerns were connected to the security of their children; for example, "how much responsibility should be given to a 7-year-old?" and "are the teachers aware of how to help and support my child?" Also, the parents assumed that the children would like to participate in an online community. The children, however, were not interested in digital diaries, augmented reality, or online communities. They wanted an optimization of a carbohydrate app that could help them manage their diabetes, provide security when on their own, and offer information when needed. As stated above, our study shows the importance of putting the end-users and their daily life situation at the center when designing new applications.

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