

Investigating issues related to pediatric diabetes education: problems and barriers

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ABSTRACT

In this work, we report on findings from a study of pediatric diabetes in everyday life, aimed at better understanding the needs of children and their parents, and the role of interactive technology in supporting them. Through analysis of a series of in-depth interviews with parents, we identified a series of key challenges in developing tools designed to support everyday self-management. In particular, we focus on and discuss educational issues as they clearly emerged as a recurrent concern in our study.

Categories and Subject Descriptors

H.5.2 [User Interfaces]: *User-centered design*

General Terms

Design

Keywords

Children, type 1 diabetes, interviews, User Centred Design.

1. INTRODUCTION

Type 1 diabetes mellitus (T1DM) is the inability of the pancreas to produce insulin, causing chronically high levels of sugar in the blood [2, 14]. To manage their medical condition, individuals need to check their blood glucose regularly, take insulin, have a healthy low-carb diet and engage in physical activity [2, 14]. For affected children and their parents the complexity of diabetes management, the required adjustment to a completely new lifestyle, and the constant monitoring are all very stressful [10]. It has been emphasized that the ability to make sense of their condition and understand diabetes to an appropriate level of detail is crucial for affected individuals [10]. Such sense making and understanding is a crucial factor in dealing with the practicalities of everyday life, and has the potential to benefit both the physical health and emotional wellbeing of affected individuals [12, 14]. In this research, we began by analyzing some of the challenges and issues in pediatric diabetes from the perspective of the affected children and their parents/guardians. We focused on everyday chronic care practices in domestic settings (home, schools, etc.) and the potential role of interactive technology as a tool for patient empowerment. We see the initial understanding and identification of the key issues and challenges in pediatric diabetes as central to understanding the extent of possible design interventions that are mindful of a User-Centered Design (UCD) approach and that aim to address real user's needs outside the attention of medical staff. In order to become familiar with the

main issues affecting these children and their parents, we conducted a series of in-depth interviews investigating the everyday practicalities, difficulties and intricacies of pediatric diabetes management, revealing that educational issues (especially related to newly diagnosed children) and potential emotional ramifications are key issues needing attention. In line with recent developments in interactive technology in health education [1, 5, 7], we outline the challenges surrounding the role of educational tools in pediatric diabetes. In the next section we offer a background overview of pediatric diabetes and an outline of models of care for children and adolescents with T1DM. Then, we discuss some of the findings of our qualitative study in pediatric diabetes self-management. We will use our data to show and highlight that issues related to the education of newly diagnosed children and their parents are of particular concern and need attention. Such findings help to identify key areas of further research and intervention. Also, we will argue the need for new educational tools that are mindful of the child's feelings and how these may improve individual sense-making.

2. PEDIATRIC DIABETES AND DESIGN

2.1 Why children with diabetes?

The proliferation of Pediatric diabetes is becoming an ever increasing concern for our society. To predict the number of cases that are expected by 2020, Patterson and colleagues [9] examined 29,311 children with type 1 diabetes between the ages of 15 & 17 for a period between 1989 and 2003. Using statistical models, they predict that the numbers of affected children younger than 15 are expected to rise by 70% by 2020, and children younger than 5 by 100% [9]. According to SWEET¹ [11], in 2011 the total number of children aged between 0-14 years with T1DM in the European region is the highest in the world at 115,700 [11]. For the same year, there were 17,800 newly diagnosed children with T1DM [11]. Williamson's [15] vision for an improved model of care for children and young people with diabetes "is constructed from a combination of effective structures and processes of care" which is "patient-focused" supporting "screening and educational interventions" by a well-resourced multidisciplinary team with the assistance of Information Technology (IT) "measuring structures, processes and outcomes of care" [15]. In reality, despite guidelines for a model of care, criteria and targets, SWEET [11] data analysis reveals a different picture, indicating problems related to quality and quantity of care and education available for affected young individuals. Only 7 of the 26 EU countries have a "quality control system of the delivered pediatric diabetes care" and only 13 of these EU countries have a pediatric diabetes register [11]. These dissimilarities are explained by the "cultural

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¹ SWEET was established in 2008 with the aim to improve pediatric diabetes care by developing of centers of reference (CORs)

differences among countries, differences in clinical governance, and lack of structured networks of interested parties with commonly agreed goals” [11]. Young patients need “continuous attention” because diabetes management “is not universal”, it should be tailored for each child depending on their development and age, with help provided by a multidisciplinary team as the “constant education and support” for the child and their caregiver, starting from “the day of diagnosis” [4].

2.2 Exploring the design space in T1DM

User Centered Design suggests that an early focus on and involvement of users is key for the development of products and services that will resonate with the end user and that will address their real needs [6, 8, 13]. The ISO9241 is a standard outlining design activities and principles of UDC where the design process is modeled around four key phases: (a) understanding the user and specifying the context of use, (b) specifying the user requirements, (c) producing design solutions, and (d) evaluating the designs [8]. All of these phases are iterated with the aim of producing high quality technology that meets user requirements. Understanding the context of use and the user’s needs is therefore crucial [6, 13] in this paper we focus on this early phase of a user-centered design process, exploring the role of interactive technologies in pediatric diabetes self-management.

Many studies were based on design, adoption and future use of technology supporting diabetes education and self-care [1, 5, 7]. Diabetes education via telemedicine was observed as equally effective as diabetes education provided in controlled groups [7]. Telemedicine technologies were considered as a great opportunity for patients living in rural places to get access to diabetes education programs [7]. According to Chomutare et al [5], in 137 mobile applications only 27 have features supporting personalized education showing that education “is conspicuously under represented”. Various computing applications (e.g. meal and blood sugar diaries, nutritional apps, etc.) are designed for “enhanced diabetes self-care”, but “their actual benefit is not well-understood and their usage and impact may be quite intricate” [1].

3. EXPLORING EDUCATION IN T1DM

To become familiar with the perspective of the children and their parents, we interviewed a number of parents of affected children. Our intention was to gain a better understanding of the general issues and everyday problem-causing factors in pediatric diabetes self-management, experienced by families in domestic settings.

3.1 Methodology

Table 1. Participants who have experience with type 1 diabetes

Participants:	Age of diagnosis:	Current age:	Participants:	Age of diagnosis:	Current age:
P1	8 years	23 years	P8	9 years	12 years
P2	10 year	17 years	P9	5 years	9 years
P3	21 months	3 years	P10	6 years	12 years
P4	6 years	8 years	P11	4 years	7 years
P5	7 years	12 years	P12	17years	24years
P6	7 years	8 years	P13	10 years	18years
P7	7 years	9 years	P14	10 years	50 years

Looking for more detailed and descriptive data of diabetes self-care practices, fourteen volunteers with practical experience of pediatric T1DM were interviewed for the period of October 2012 - June 2013. The age at which their children were diagnosed varied between 21 months and 10 years old. 3 of them were adults diagnosed at young age (see Table 1). The in-depth, semi-structured interviews lasted between 40 minutes and one hour. The questions were open-ended, providing flexibility and genuine access to the participant’s point of view and their specific concerns related to diabetes. All the interviews were audio recorded as the data was transcribed into text and analyzed using MAXQDA qualitative analysis software. To maintain the

anonymity of the volunteers and the medical facilities in this study we are using the abbreviations for participants P1, P2, etc. As said, educational issues emerged as a recurrent topic in the interviews. The following section reports some of the most evident categories of data revolving around this key issue.

3.2 Diabetes education at hospital and home

3.2.1 Parents and children education at hospital

Newly diagnosed children with T1DM and their parents get an outline of what diabetes is on the day of diagnosis in the hospital. “We were told actually from day one that she used to do this and after that she shouldn’t depend on in home. But we were told in the (name of the hospital) that from day one make sure that she takes her checks for herself and inject herself. So she was taught all that and we were shown the way how to do it, but we were strictly told that she had to do it herself from day one.” (P1). “...they showed her what to do on the first day...” (P5). Usually this first-day education focused on the practical aspects of taking insulin injections and using different artifacts to measure glucose levels. The use of teddies or dolls to show how to inject is often used to transfer this knowledge “...we were injecting the teddy...”(P4), “...she compared her to the doll and went through the areas and why she needed it...” (P7), “...a rubber cushion and they injected that...” (P5) Information was however reported as vague when it came to understanding the nature of the disease. Staff members were prone to talk to the parents instead of children themselves “...they didn’t really explain it to our daughter, they more explain it to us...” (P6). Parents reported that these educational practices at the hospital were very traumatic because many factors influenced the emotional state of their children. Some of parents pointed to fear of the illness “she probably went through all the emotions fear everything else” (P6), and other experienced problems with needles or blood phobia presented by their children “...hated anything got to do with medicine or needles or anything like that...” (P11) and “She had a massive needle phobia, so it wasn’t a great time to get your child with the needle phobia so it was quite difficult at the start trying to teach her that.” (P4) For those children who were very young at the time of diagnosis (e.g. 4 or 21 months) the education was given to their parents, and they had to decide what their children needed to know and at what age their child would learn about diabetes self-care practices. “He hasn’t asked yet (about diabetes), we have started to try to explain it to him. He doesn’t obviously like getting his set changed (using insulin pump), because the needle hurts him. So I try and tell him “This will stop you are feeling sick, this needle will make you feel better.”” (P3, on the time of interview the child was 3 year old).

Education for parents typically focused on how to manage the disease after they returned home i.e. injecting the child with insulin, understanding the relation between insulin and carbohydrates, symptoms of hypo- and hyperglycemia (conditions explaining low or high blood glucose in diabetes), keeping a diary, etc. “They explained it like you have just started school. They were brilliant; they will show you everything and telling you word by word what to do. Every time she was doing an injection, somebody has to show her. You can say to them “What I am supposed to be look in at?” And they will tell you. The nurses will tell you, then the diabetes team will come up every day to see you and train you for all the different things. I think that’s why they kept her in for so long, because they wouldn’t let me and let her to go home until I was trained.”(P5) Many parents thought that it was very difficult to learn all of this important information during their short stay at the hospital. “I know it is easy now looking back

but I think at the time it was very overwhelming... There is just so much, you are trying to take in about the insulin and carbohydrates. In exchanges nurses says how many carbs this is worth, how many carbs that is worth. That was all new to me, I remember turning to my husband and saying "I can't imagine somebody who knew nothing about diabetes doing this". He was in, he knew nothing about diabetes and then he was relaying a lot on me. That was really hard, I do everything good for the kids, they something like that just to explain look what happens. I think that at the start, there are just so much, it is so overwhelming." (P4). One father explained that the information taken in the first days "was very much the mechanical use of the needles and taking measurements" but "they didn't really talk to us about food or how it impacts" (P6). At the first year, the honeymoon period (this is a period of months where the remaining beta cells in the pancreas are still producing small amounts of insulin) was very difficult as it wasn't discussed a lot and the "lack of information at the very start which was kind of where you are left" (P2). A parent rates overall education "as poor" because there was no education "on how to deal with different scenarios, you're left at home to your own devices and when a scenario comes up you have to come back or call in" (P7).

3.2.1 Parents and children at home

Leaving the hospital brings many doubts, fears and questions. Some of the parents lacked confidence in dealing with diabetes in a different situation. "We were so scared. He didn't get a low in the hospital and they were kind hoping he would. He actually got sick a week after we got home. He caught a flu and was very low and we couldn't get him up. He didn't want to eat anything. I was trying everything to try keep him up but it was a scary time." (P11) Returning home presented a challenge for all of the parents; they needed to deal with their new circumstances alone. "After a week we were sent home and it was kind of difficult thing because normally when you leave hospital you are fixed, so we had to change our habits. We had to take records, make our own observations and make decisions based on those observations. Although we were given a bit of knowledge it was not enough..." (P6) "It's like bringing home a new child, you've to watch the diet, write down everything the child has been eating. The times you took the injections, what you took, what were their bloods two hours after. So you're constantly pricking her finger, constantly monitoring, reading labels on food." (P8). A mother complained that the education at the hospital "is only medical" (P8) and "the human side of it, you don't really know till you come home and then there isn't really anyone to turn to" (P8). Other concerns were related to carb-counting education "...we were never told about the carbs, well we were told that it's really only carbohydrates on the back on the wrapper that you need to look at. The Carb counting is only something new to us really because we're looking for the pump..." (P11), "the different slow acting carbs, there is absolutely no education around that..." (P7), "...six months guessing not knowing how to really count carbohydrates, how to do anything..." (P2), "...loads of people will be waiting to get on pumps and they'll be asked: Can you carb count? And there's nowhere for them to learn." (P9)

One week's education in the hospital is not enough for children to understand how to deal with self-diabetes management at home. Parents try to educate their children about the carbs-insulin relationship and why the injections are part of the treatment. "It was just one puppet had C for carbs and one puppet had I for insulin. So they were on a little seesaw...and I said "What happens when you eat?" and she goes "Your carbs go up", so she

knows what happens when she eats, "What do you need to make your carbs not go up?" and she goes "The insulin", so when you give the insulin, you see the seesaw balance." (P4) Children struggle to recognize the symptoms of hypo- and hyperglycemia as all the symptoms are new for them. Their parent's role as educator becomes critical. "...tell mummy how you feel?" and she said "I am really, really hungry". "This is a hypo, you need to remember it" (P4), "I told her that when she has high that is why she feels thirsty." (P5) Diabetes complications were a very emotional theme for discussion. Some parents used examples from their daily routine to explain the implications of improper care. "But I used to say to her, "Now you need to look after yourself". And when I'd be putting on my night cream I'd say "see, mommy's looking after her skin." So when I'm older, I'll look better than those who didn't bother looking after their skin. So if you look after your Diabetes, you won't incur problems later down the line that people might if their careless now." (P8)

'Pete the pancreas', an illustrated children's booklet explaining T1DM, was identified by the parents as the educational material provided to their children at the hospital. "They only provided us with those set of books for Pete the pancreas" (P6). When mentioned, some parents did not see the book as good enough, pointing out the limitations of "deep medical detail as well around not only the insulin, the doses, carbohydrate counting, the biology and everything else" (P6) and "I want to see clear and accurate explanations of the disease but only up to a certain age and appropriate level. I don't want to see talk about amputations and stuff like that...I want to see role models...I want to see, what we say to care givers..." (P9). A mother shared that the book didn't help her when she tried to explain the relationship between the carbs and insulin "...Pete (the book) doesn't work anymore..." (P4). Despite the use of engaging visual material, Pete is too general and does not seem to speak the language of the user. It is medical in a way that might upset some children, but it is also not medical enough for those who want to know more. In reducing diabetes to its medical categories (glucose levels, insulin, cells) it also fails to ground it in the context of everyday life. In this sense, it is normative more than practical, and after a while it is not used any more. When a child is diagnosed with type 1 diabetes, their "carefree days to a certain extent" (P1) are over. "No day is ever the same though, no matter how hard you try, and it's one of the most disheartening things, because you're trying your best and it's a 24 hour job." (P7) "Things change every day ..." (P2). There is always something new to learn for diabetic children. On the contrary, education is static and occurs in predefined moments.

3.2.2 The Child's Emotional State

Explaining the variety of difficulties in everyday diabetes management, most of the parents share their child's emotional state. Their feelings and emotions are very strong, they struggle to accept the diagnosis, they hate it, they are devastated, they ask why? "She struggled I think a lot with the diagnose, she hates it...she hates everything about diabetes... I don't think that in her heart she has fully accepted it...Every day with tears she'd say "I hate diabetes, I hate my life. Why did God give it to me?" (P4) "...would be more or less in a certain amount of denial about it, in that she doesn't like to talk about it..." (P10) "I wish I didn't have this, you know that don't you? I wish I never got Diabetes." (P8) "...she still has days with "I hate this" (P5) "...there was a lot of "why me?", "Why did I get this?", "I don't want this." (P7) "He goes and he lies on his bed and cries till he comes out of it." (P9) "...she had trouble accepting this, yeah...You could see she was devastated." (P1)

4. DISCUSSION

Our initial qualitative investigations helped us to highlight a series of key issues around pediatric diabetes self-management that will inform our future research as well as the exploration of the available design space for intervention. Together with potential users (parents and children) we identified limitations in education for newly diagnosed children. We discovered that education is an essential element in diabetes care as it helps with grounding new care practices into the daily routines of a family. We learned that current education tends to be too general, normative and universal. The data analysis showed that current educational practices seem too inadequate to ensure that parents and children are well equipped to manage the illness in a domestic environment. When they leave the hospital, families are left alone to deal with a series of difficulties they are not familiar with (e.g. the emotional state of their children). At home, a parent first must acquire detailed knowledge about diabetes management and then become an educator of diabetes self-management practices. Children need to know how to interpret bodily signals, the relation between insulin, carbs and physical activities, how to behave during sick days. Each child is a unique individual. Children's needs and care standards change with their developmental stages of life, and they need constant acquisition of new self-management skills. A negative attitude toward the disease charged with negative emotional states can be detrimental when dealing with uncertain outcomes. The parents pointed out the limitations of educational materials for children with T1DM but also claim that written information combined with practical training and guidelines are imperative in preventing the risk of long-term complications. We believe this direction of research needs to be explored further. Accordingly, it is our intention to further study current delivery of education². To try and address the issue of the limited educational tools available, we would like to explore the role of new interactive media (such as digital storytelling, interactive eBooks). Some research in the ambit has been done [16]. "Digital stories have great potential for teaching health and management of chronic diseases" but "they have not been thoroughly explored as a delivery method for promoting health and well-being in children" [16].

5. RESEARCH LIMITATIONS

Considering that parents are very busy with the constant care of their sick children, they have struggled to find time to be interviewed and the recruitment of the volunteers was a challenge for the researchers. The difficulties in interviewing the children themselves are still the main limitation of this study; not only for ethical reasons, but also for their resistance to talk about diabetes, often seen as something that "makes them different". Two problems with child participation in this qualitative investigation emerged: the child's emotional state and their requiring constant adult supervision.

6. CONCLUSION

There is still much to understand about both the children's and the medical profession's perspective regarding continuous diabetes education in domestic settings, and the methods and practices that may be implemented in the design of novel educational technology. The study helped us to focus our research and to fine-tune our research questions toward a better understanding of T1DM in everyday life, its educational requirements, and the

potential role of interactive technology. To overcome the challenges of accessing children we have decided to move to more design oriented methodologies such as design probes [17] and design games [3]. Presently, the authors have developed a series of probes and design games inviting children to create content reflecting on their experience. These methodologies have been very generative of ideas (from the children themselves) about possible improvements to current educational tools. We are working on a paper reporting on this second phase of our project.

7. ACKNOWLEDGMENTS

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² One of the authors will soon join a national program for diabetes education based called CHOICE (carbohydrate and insulin collaborative education)