Designing for children with diabetes: exploring the role of interactive media in diabetes education

Damyanka Tsvyatkova
Interaction Design Centre
University of Limerick
Ireland
damyanka.tsvyatkova@ul.ie

ABSTRACT

This research is concerned with the problems and issues of pediatric Type 1 Diabetes Mellitus (T1DM) care from the perspective of children and their families, and it explores the potential of interactive technology design to empower the patient. This paper reports on the design research phase of the project which aims to outline the work completed in the first two phases (i.e. analysis and design) of a User-Centered Design (UCD) process, and how the design of an educational eBook for newly diagnosed children aged 8-12 years with type 1 diabetes links to the data collected. Methods of UCD, Participatory Design (PD), Design Probes (DP), Cooperative Inquiry (CI) and Informant Design (ID) were applied to support children and parents' participation as well as to examine the role of the users in the design process.

Categories and Subject Descriptors

H5.2. **Information Interfaces** and Presentation (e.g., HCI): User Interfaces (Evaluation/methodology, User-centered approach)

General Terms

Design

Keywords

Participatory Design, User-Centered Design, type 1 diabetes, children, eBook.

1. INTRODUCTION

This research has three objectives: a) Explore the potential of design in pediatric diabetes management by learning more about pediatric diabetes care, with particular attention to everyday issues in self-management and the perspective of children and their parents; b) Conduct a User-Centred and Participatory Design (PD) process to explore the role of interactive technology (currently identified as an interactive eBook) in an identified area of concerns (currently identified with education); c) Evaluate and reflect on the impact of the designed solutions and the participatory methodology. This paper focuses on the chronic illness diabetes and educational technology supporting self-care practices. It also provides information on the work completed in the first iteration of the User-Centered Design (UCD) process: understanding the context of use and developing different design ideas. In order to identify the problems and issues in daily diabetes management while working on the first stage of UCD, fourteen semi-structured interviews with individuals who have

direct experience with T1DM were conducted. Through the analysis of data, two main issues emerged [15]. The first concerned the current limitations of the educational material used to provide education to newly diagnosed families. The second concern was the impact of negative emotions experienced by the young children in connection with self-management [15]. An appreciation of these two key issues helps to identify potential areas for a design intervention exploring new approaches to education based on interactive technology. In this particular case, the idea is to design an interactive educational eBook for newly diagnosed children 8-12 years of age with type 1 diabetes and their parents, as well as to explore design techniques and methods that allow user participation in such design processes. To gain an understanding of the issues surrounding pediatric diabetes care is problematic, not only for ethical issues but also for the difficulties in finding children who are happy to talk about their experience with diabetes and gaining access to their domestic practices [15]. In order to become familiar with their world and at the same time explore prospective elements for design, a series of PD methods were developed. Based on initial information collected by interviewing parents, a series of Design Probes (DP) [17] were developed. As the probes were collected, a series of PD workshops were carried out: one with a family who has a child with diabetes, and two sessions with healthy children and their parents. These workshops were inspired by PD [3, 12] methods and Informant Design (ID) [3]. The generated data will form the basis for the design of mock-ups and low fidelity prototypes of an educational interactive eBook to be tested with the participants.

2. T1DM AND CHILDREN

As of 2011, 155,700 children (0-14 years) in Europe have T1DM [13]. Even with modern treatments available, 12 years after diagnosis, 50% of children developed complications based on poor glycemic control [11, 13]. Type 1 diabetes is a chronic condition characterized by high blood glucose level caused when the pancreas stops producing insulin [4]. As caring for diabetes requires daily attention, affected individuals need to understand the importance of disease management by learning multiple self-care practices. Diabetes management includes administrating artificial insulin through injections or the use of an insulin pump (a computerized device that mimics the human pancreas and constantly delivers insulin to the body), having a healthy diet, counting carbohydrates in the food, partaking in physical activities, learning to recognize symptoms of hypo- and hyperglycemia (very low or high blood glucose) and applying the appropriate treatment [4]. Education is a key factor; it must deliver information and practical knowledge to enhance self-care and to accommodate different patient needs [4]. Acknowledging that children are not adults, all these daily diabetes management tasks are dependent on their physical development, maturation and ability to practice self-care [4, 10]. Moreover, educational interventions are a continuous process tailored to children's

personalities and appropriate to their growth and development process [6, 10]. Raising a child with diabetes requires different roles from the caregivers; they need to supervise their children to assure appropriate self-management capability, helping them to build self-confidence in skills and autonomy [8] while functioning as diabetes educators. First they need to acquire knowledge about diabetes and then help the children learn about self-care practices. The usage of appropriate resources (e.g. books, images, videos, internet, etc.) to support their child's pursuit of understanding and important learning outcomes is essential; the materials need to be suitable for their age, interests and individuality [9]. The parent's support is crucial in helping the child gain the experience and knowledge needed to develop an individual strategy for understanding diabetes [8].

3. EBOOKS IN HEALTHCARE

Interactive eBooks are a new medium, a graphical technology for mobile devices supporting new forms of experience for the reader beyond the media of paper and written words. Considering all these possibilities of the enhanced e-books (EEB), the main goal of the interactive eBook workshop IBooC2013 for children was to define "key directions for future research in the design process and implementation of this kind of books" [5]. As new learning resources, the eBooks had very little ambit in the design of education in healthcare for chronic illnesses [16] and "they have not been thoroughly explored as a delivery method for promoting health and well-being in children" [16]. There is a variety of disparate technologies [2, 7] useful for children with diabetes but an eBook could easily support, but not be limited to, a visual story for the human body and digestive system, stories or games for carbs counting and healthy food (e.g. what are vitamins and minerals), games or stories for symptom recognition (hypo- and hyperglycaemia), a glossary of the terms used in diabetes, how to design an emergency plan at home or at school, a diary for diabetes (insulin log and carbs) with a private diary and alarms informing the user when to take medication, or practical video lessons on using insulin and glucometers (technology helping to measure blood glucose) that can be used by the child in the hospital when diagnosed and later at home with parents.

4. METHODS

Focusing on the user's involvement and participation in the design process, several approaches were planned for the development of educational technology: two iterations of four stages of UCD lifecycle based on ISO9241 – 210: 2010 (analysis, design, prototype, test and evaluation of the prototypes) [1], semi-structured interviews, DP [17], PD [12], Cooperative Inquiry (CI) [3] and ID [3]. UCD is focused on the users; it is described as a problem solving process aimed to design a technology that supports users' requirements and needs [1]. Semi-structured interviews were used to collect qualitative data about users' experience with diabetes care. DP [17] is a set containing purposefully selected playful tools with the aim of gaining information about user's everyday experience by self-documentation. The DP method was applied in order to overcome the barriers of ethnographical study (observation in a sensitive environment), to encourage children's involvement (e.g. dealing with the negative emotional state toward diabetes) and ethical considerations in working with children with T1DM (parental care is required to ensure children's individual needs). PD [12] supports direct involvement of stakeholders in a collaborative partnership with designers in all activities of product development e.g. design, building and testing of the prototypes. CI [3] and ID

[3] are two methods used to facilitate the child-design relationship in the design process. CI supports design partnering between adults and children as the "primary goal is elaboration" [3] whereas in the ID method, the goal is to build "dialogue" [3] between children informants and designers, to provide feedback. In order to accomplish the design process and to produce different fidelity prototypes, a series of interactive workshop sessions with volunteers was scheduled. In the second iteration of UCD, medium tech-prototypes will be built, tested and evaluated in real settings (clinical and domestic environments) with newly diagnosed children of T1DM.

5. PROGRESS TO DATE

In the first two stages of UCD fourteen interviews were conducted and collected data analyzed, DP analysis of seven probe sets and three design workshops were accomplished. Collected materials described below will be used to build low-tech prototypes in a series of paper prototyping workshop sessions planned for the end of March and April 2014.

5.1 Participants

Taking into consideration that children fall under the category of vulnerable participants, care and protection during the study is extensive. For this research, all ethical approvals were obtained and multiple recruitment strategies (using university mailing lists, parents support groups for children with T1DM on Facebook, national schools, kindergartens and GP surgeries) were applied to for different stages of the planned work. The researcher traveled to meet fourteen individuals (Table 1, for anonymizing participants they are labeled P1, P2, etc.) to examine various personal experiences in dealing with pediatric diabetes. Seven families (Table 1, P4, P5, P6, P7, P8, P9 and P10) decided to continue their participation in the DP method, having children with T1DM between the ages of 8-12, with one family (Table 1, P8) participating in the first design workshop session for collaborative storytelling using PD [12] and CI [3]. Fourteen healthy children and their parents from the local voluntary group "Sunflowers" were recruited for the second and third design workshop sessions - "Traveling through the human body" (eight children) and "Superhero is sick" (six children) respectively - employing the ID [3] method.

Table 1: Participants in the interviews and DP method

Participants	Age of diagnosis:	Current age:	Participants	Age of diagnosis:	Current age:
P1	8 years	23 years	P8 (continue with DP)	9 years	12 years
P2	10 year	17 years	P9 (continue with DP)	5 years	9 years
P3	21 months	3 years	P10 (continue with DP)	6 years	12 years
P4 (continue with DP)	6 years	8 years	P 11	4 years	7 years
P5 (continue with DP)	7 years	12 years	P12	17years	24years
P6 (continue with DP)	7 years	8 years	P13	10 years	18years
P7 (continue with DP)	7 years	9 years	P14	10 years	50 years

5.2 Interviews

Exploring issues affecting health and well-being in pediatric diabetes, fourteen semi-structured interviews (Table 1) were conducted. They were digitally audio recorded, transcribed into text and coded using MAXQDA qualitative analysis software [15]. The main goal was to identify users' needs and any issues in diabetes management care experienced by parents and children and how new design interventions can support users. The majority of volunteers described their main problems as being diabetes education at hospital and at home, the shortage of time allocated to learn diabetes care (usually for a week in the clinic) and the lack of appropriate educational materials for children such as books, images, games, videos, etc., that can support the parents' and children's educational needs outside the clinical environment [15]. They also pointed out that the only education for children is in the clinic settings after the children were diagnosed with T1DM

and it is primarily about the self-care practices (taking insulin, measure blood glucose, etc.) but less informative on the nature of diabetes or how to deal with different scenarios (symptom recognition of hypo-and hyperglycemia, sick times, etc.) [15]. No structured education is provided for children 8-12 years after they leave the hospital. Learning about users' problems and requirements helped to identify what technology to design - an interactive educational eBook that may empower patients - meeting individual educational needs of the users in different settings.

5.3 Design Probes

Figure 1: Design probes flyer and some produced materials

DPs (Figure1) were used to avoid and minimize ethical challenges in working with children (parental supervision is required), to collect data unobtrusively by applying ethnography in sensitive settings (home, school, etc.) and to deal with negative emotions generated by the illness [15]. This method was very successful in shedding light on the health-related issues experienced by young users through facilitating their participation in the first stage of UCD by self-documentation. By providing rich and valuable data of children's lives dealing with their illness and environment, probes also helped to reveal children's perceptions of the illness, their struggles in daily care, their feelings, and their autonomy in self-care. Some of the activities (e.g. Design your own Recipe Book, Design Collage/Poster and Super Hero and a Story of his/her Power) were designed in such a way to gain potential insights into the design of the educational eBook. Seven families participated (Table 1) in this part of the research but only five of the sets were returned to the researcher. Seven activities were designed for diabetic children 8-12 years of age (Table 2). 1) Disposable Camera and a list with requested pictures of things that children like/dislike; 2) Using of safety art and craft materials to design technology that can help them in their daily life; 3) Send a Postcard to people that they know e.g. doctor, granny, teacher, cousin, etc.; 4) Design Collage/Poster for imaginary World Diabetes Day; 5) Kid's diary about their daily activities managing diabetes; 6) Work with modeling clay to create a figurine Super Hero and to tell a Story of his/her Power and 7) Design a Recipe Book for breakfast, lunch, dinner and snacks. Parent's Problem Solving Diary was the one activity for their parents to write down own concerns, feelings, emotional reactions, and personal control of different situations in dealing with diabetes.

Table 2: PD responses

Activity	Responses
Disposable camera	3
Technology Gadget Design	4
Send a Postcard	3
Design Collage/Poster	5
Kid's diary	2
Super hero and a story of his/her power	4
Design your own Recipe Book	1
My problem solving diary	4

5.4 Design workshop sessions

The children's participation in the design process was facilitated by using the CI [3] method in which children are involved as design partners, and ID [3] where the role of the children is to be informants. Using collaborative storytelling, three design workshop sessions were organized and each of the sessions was planned to be 45 minutes in length. In the first small workshop

session organized in the Interaction Design Centre (IDC) building, the designer, together with one family (12 year old child who has type 1 diabetes and her parent), collaboratively played different scenarios emphasizing the role of diabetes management in different environments (at hospital, at school, at the shop, etc.). For example, participants were asked to describe their first experience with diabetes, what was new and unusual for them, what education in the hospital they received, how they now buy food in the shop, what do they need to do take with them for a holiday or school, etc. The data collected (Figure 2) helped to discuss and identify features, educational needs, images and text that would need to be implemented in the eBook design.

**Figure 2: Materials produced on workshop session one**

The interactive eBook will be for newly diagnosed children. These children will not have any information about the causes of the illness as well as any self-care practical experience with diabetes. ID supports children's participation so to inform the designer about their knowledge specific to a certain field, to learn more about children's language, experience of the world, their awareness of healthy food, their experience with the current technologies, etc. Fourteen healthy children (between 11-12 years) and their parents from the voluntary group "Sunflowers" participated in workshop session two 'Traveling through the human body' (Figure 3) and session three 'Superhero is sick' (Figure 4). These sessions were held in a community centre that hosts many other group activities.

Figure 3: Workshop session two

To increase the children's contribution and to promote comment and discussion, art and craft materials and storytelling cards that were specially designed for both workshop sessions were used. In the first workshop session, children developed a story of two children who decided to travel through the human body. Young participants (eight girls) played with modeling clay, forming figurines of the boy and girl (the main characters who will have a trip inside the human body), the technology (submarine) used for traveling and human body organs that characters see during their trip (Figure 3). Children also expressed their understanding of how organs work, placing them in the outline of the human body (built from foam). For the second session, children (six girls between 11-12 years) were asked to describe a story in which the superhero is sick, he/she needs to take medicine regularly, have a healthy diet and sport. They need to help the superhero by describing the technology that will remind the superhero to take medicine with every meal. Children were asked to categorize foods into the healthy or unhealthy group, explaining to the superhero why healthy food is important and what methods they can use to motivate the superhero to do regular physical activities. Colored pencils and markers were used to create images and dialogue boxes, to develop the main characters in the story, the Superhero and the Doctor. Developing the story, they elaborated on the dialogue between these two characters (trying to speak in

the language of the characters), explained the settings (e.g. Superhero's home and GP surgery), and described the actions and behaviors of the Superhero and Doctor (Figure 4 shows some of the materials that were prepared).
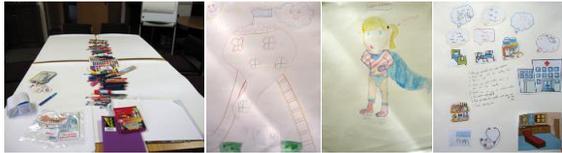
Figure 4: Workshop session three

The imaginative roles played out in these two sessions were very beneficial for generating ideas through the stories, emphasizing the essential elements for effective digital storytelling.

6. DISCUSSION

In PD all parents, children and designers work together to develop a technology. There are two challenges that occur when applying PD to the project: 1) the recruitment of the volunteers and 2) the negative emotional reaction of children towards diabetes. The first challenge is linked to time and diabetes care. Parents are under constant time pressure as they manage pediatric diabetes in their children. They found it difficult to arrange time for interviews and also to participate in the workshops planned during the period of July-September 2013. Problems with children's participation in the workshops stems from the different regimental eating patterns for each child and the hypo- and hyperglycemia which can occur at any time. The second challenge arises with the methods and techniques used to involve children in the design process. If children don't like to talk about diabetes in regards to their negative emotional state (emotional challenges that diabetes presents for them [15]), what methods and techniques will be appropriate? The theme is very sensitive and emotionally concerning, raising issues of ethical boundaries. The emotional state of users in the CI is crucial as the new design partners are young and emotionally vulnerable. The work of the designer became difficult; multiple plans in order to adjust with any unwanted (emergency) situation are needed. The flexible shifting between designer, pedagogue or psychologist role seems to be problematic. This challenged the designer to search and suggest less invasive design techniques that will encourage positive emotions (e.g. DP, collaborative storytelling, game playing) to increase creativity, productivity and willingness, helping children to contribute their knowledge and experience in the field. Of course the role of healthy children in design was considered as also important in helping to find the appropriate language, content and information that an educational eBook needs to support.

7. FUTURE WORK

The planned work for this project is to finish the first iteration of the UCD by organizing workshop sessions for building low fidelity, paper based prototypes with children and parents in the camp organized by the Diabetes Organization and then several workshop sessions for testing and evaluating. This research will continue for eighteen months as several workshops are planned for this period for a reiteration of UCD. There are also planned meetings with medical professionals e.g. dietitians and diabetes nurses to garner their experience in the field.

8. CONCLUSION

The dissertation research is focused on what technological intervention can do to help children and parents in pediatric diabetes education in both clinical and domestic settings. Using UCD, PD, CO and ID will help to explore the user's role in the design process as well as how these methods support the design of interactive technology. Analysis of fourteen interviews and seven DP sets were carried out to learn from the users' (parents and children) experience in diabetes care and show the direction of the design: an educational interactive eBook for newly diagnosed children with T1DM and their parents. Three design workshop sessions were completed as a part of the first iteration of UCD elaborating on some ideas for the design. A series of workshops are planned to build low tech paper prototypes to test and evaluate proposed ideas.

9. ACKNOWLEDGMENTS

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