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Design an educational interactive technology for children with type 1 diabetes: exploring ways to better involve users in the design process

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Abstract
The project reported in this paper aims at improving our understanding of everyday diabetes self-care practices in children and their caregivers. In our work we are concerned with the role of design in developing interactive educational technology that could improve young users' ability to make sense and learn about diabetes management. In particular, we explore a series of collaborative and participatory design methods that may better support users' involvement (e.g. children and parents) in designing this technology. In previous papers, we brought attention on the limitations of current educational materials as pointed out by the participants. We also discussed how applying different methods such as Design Probes (DP), Cooperative Inquiry (CI) and Informant Design (ID) facilitated the generation of important data for the design of an educational interactive eBook for newly diagnosed children with diabetes.

In this work, we focus on co-design with affected children and show how it is more complicated than usual. We show how designing with affected children demands a specific approach and attitude to overcome their emotional problems caused by the experience of living with diabetes. This emphasizes the significant role of the designers in selecting appropriate methods, techniques and tools with the aim to best support participants' involvement for eliciting more articulate responses. Involving both healthy children and children with diabetes in the design process helped to compare their different inputs as influenced by their "roles" in being "experts", qualified by their dissimilar experience generating rich data for technology developing and prototyping.

Keywords: children, type 1 diabetes, educational technology, User-Centred Design, Co-design

Introduction

According to The Lancet (2012) "all people are patients at some point of their lives". However with some chronic diseases such as type 1 diabetes, the lives of affected young individuals and their families change forever, making them patients for the rest of their lives. Becoming a young patient newly diagnosed with Type 1 Diabetes Mellitus (T1DM) inevitably leads to significant changes in personality, reflected in the child's growth and emotional development (Danne and Kordonouri, 2007). Diabetes self-management education regarding the taking of insulin injections (or using the insulin pump[1]), having a healthy balanced diet (counting the carbohydrates) and regular physical activities is crucial for improving the quality of life in young patients (Lange *et al*, 2014). This education is a long process that should be carefully planned, age-appropriate, delivered at regular intervals and be easily accessible to all children and parents, involving them in the learning activities at the time of initial diagnosis (Lange *et al*, 2014).

This research aims 1) to gain a deeper understanding in the context of paediatric diabetes everyday care experienced by children and parents in domestic environments and to explore the potential support of an Interactive Technology (IT) helping families to develop appropriate (self)care practices, and 2) to explore a series of collaborative user-centred (ISO9241 – 210: 2010[2]) and participatory design approaches (Muller and Druin, 2009; Mattelmäki, 2006; Druin, 2002; Scaife *et al*, 1997) in an attempt to facilitate better users' participation (e.g. children and parents) in the technology development and design. In our work we found that some of the problems experienced and identified by affected individuals were related to the diabetes education provided for newly diagnosed families (Tsvyatkova and Storni, 2014a). This helped us to identify critical needs and to explore the role of IT in developing an educational eBook for newly diagnosed children between 8-12 years of age with T1DM. In order to deal with the challenges related to the emotional implications for children coping with diabetes (Tsvyatkova and Storni, 2014a) and given the difficulties in collecting data in sensitive settings, we decided to develop a set of Design Probes (DPs) (Tsvyatkova and Storni, 2014b). These activities were cautiously selected with the aim to enable children (8-12 years of age) to explain their everyday experiences with diabetes through self-documentation. The aim was also to enable them to generate ideas for the e-Book design process. Three co-design workshop sessions were organized with healthy children and children with diabetes, incorporating techniques of collaborative storytelling applying Cooperative Inquiry (CI) and Informant Design (ID) (Tsvyatkova and Storni, 2015). This helped to produce various data in identifying key functional and aesthetic features, story characters, narratives, dialogue, etc. for the eBook. The children involved in the design had different "roles"- as

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[1] Technology that simulates the human pancreas and administer the human body with insulin every few minutes.
[2] Ergonomics of human system Interaction–Part 210: Human-centered design for interactive systems (formerly known as 13407), International Standardization Organization (ISO) in Switzerland.

"design partners" and "informants" - respectively qualified through their experiences of having diabetes and being a healthy child.

This paper reflects on the designer's recognition of the sensitivity required when working with both sick and healthy children. The selection of appropriate tools that enable sick participants present their thoughts and feelings in an effective way during the co-design without causing a negative emotional state is crucial. Also, it is important to develop new coping strategies in dealing with negative feelings (if any occur) during the collaborative work with children with type 1 diabetes. Working with a small group of sick participants helped the designer to convey a level of comfort for child participation in the design. Child input in the technology development was significant, the need of training to work as a design partner was not observed. Storytelling technique can be an effective tool to elicit users' responses and each child could be encouraged to express themselves openly ensuring equal opportunity for active participation.

Participatory approach in IT design with children with T1DM

Street and Rimal (1997) defined IT as "computer-based media that enable users to access information and messages in the mediated environment". A wide variety of IT for children with type 1 diabetes (Lieberman, 2012; Pentland, 2004; Kim, 2011) was developed with the aim to assist these children to better manage their chronic condition but there is a lack of clarity on the children's role and involvement in the entire design. Limitations pointed out by Aldiss and colleagues (2015) for the development of supportive technology for patients with long-term conditions are "the poor methodological quality" and "the lack of involvement of children and young people in the design". For example, many studies were focused on co-design (Druin, 2002; Scaife *et al*, 1997; Guha, Druin and Fails, 2012; Markopoulos *et al*, 2008) with healthy children, but they do not bring the same experiences to bear on the challenges of being a design partner, as opposed to children who have chronic diseases. This clearly brings into question whether these techniques and methods developed for children's participation in technology design - that are widely discussed in academic literature - are also appropriate for designing with young patients. How does the designer select the tools that may facilitate sick children to collaborate actively in the design process, provoking children's willingness to express their experience, ideas or to release their feelings without hurting young participants emotionally? Guha, Druin and Fails (2012) explained that children "at the beginning of their tenure as a design partner" need training. Do children who have never been a design partner need education to work as equal stakeholders when they have to explain their own experience gained through living with the illness? Trying to answer these questions, we examined different participatory co-design methods supporting the work of children having T1DM (between 8-12 years of age) in the whole design process[3] of the educational interactive eBook development as design partners.

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[3] For now are completed only the first three phases of the UCD, first iteration.

Methodology

As we mentioned earlier, users' participation and input is essential for this research as this helped us to explore a series of co-design and user-centric methods for eBook development and evaluation in an iterative fashion.

Recruiting participants

Young participants aged between 8-12 years who have T1DM were recruited through a series of strategies such as the use of the university mailing list, contact to the 'Sweetpea club'[4], Diabetes Ireland[5] association and to different parents' support groups for children with diabetes on Facebook, emails sent to national primary schools, and flyers distributed in kindergartens and GP's surgeries. Considering that educational technology is for newly diagnosed children who may not have any experience with the chronic disease and its treatment, we also recruited healthy children from the voluntary group "Sunflowers"[6].

CI and ID are methods developed to support children's participation in design to ensure different forms of their involvement as design partners through the product lifecycle and as informants offering inputs during those specific stages of technology development (Guha, Druin and Fails, 2012).

Table 1: Participation of the children in the design phase of UCD

Session	Design Method	Materials	Participants
One	CI and PD	A2 white paper, coloured pencils, images	One 12 year old diabetic child and her parent
Two	ID	A deck of cards, outline of the human body, pipe cleaners plasticine, buttons and feathers	Eight healthy children aged 11-12 years
Three	ID	A deck of cards, images, coloured pencils, A4 white paper	Six healthy children aged 11-12 years

Applying CI for the design phase, we organized one workshop session in which our design partner was a child with T1DM (diagnosed at age 9) and two sessions with healthy children (N=14) as "informants" using ID (Table 1).

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[4] This club is for children who have T1DM organized by Diabetes Ireland.
[5] Diabetes Ireland is national charity organization supporting people with diabetes.
[6] It is a club for Russian-speaking people and their bilingual children.

Workshop sessions

For the design stage we had two different groups of children: *experts* on *'being a healthy child'* (using ID) and *experts* on having a certain level of expertise obtained by 'living with diabetes' (applying CI). Collaborative storytelling was selected as a method for all co-design workshop sessions helping to generate data for the eBook development and design. Young participants were equipped with a wide variety of materials (Table1) to facilitate the children's involvement in storytelling, to give some direction for creative thinking/imagination and to improve the child-designer communication. The co-design sessions (each lasting between 45 minutes and one hour) were carried out in different settings: in a meeting room in a University Building and in the community centre where the 'Sunflower' group was located (Tsvyatkova and Storni, 2015).

Ensuring that the planned intervention corresponds with the participant's needs, in the first co-design workshop session for idea elaboration, (Druin, 2002; Guha, Druin and Fails, 2012) we collaborated with one child with diabetes and her parent. Using the art materials (Table1) we built a series of scenarios exploring places (e.g. at home, at school, at hospital, at the shop, etc.) and the corresponding activities related to diabetes self-management. For example, scenarios were created on the participants' first experience with diabetes when the child was diagnosed in the hospital, the activities in treating hyper- or hypoglycaemia[7] in the school, management tools for travelling with diabetes etc. (Figure 1). Working with the scenarios, the participants elaborated on the different types of questions that they had in different situations, their emotional response to their chronic illness and their knowledge acquired on diabetes self-management practices (Tsvyatkova and Storni, 2015).
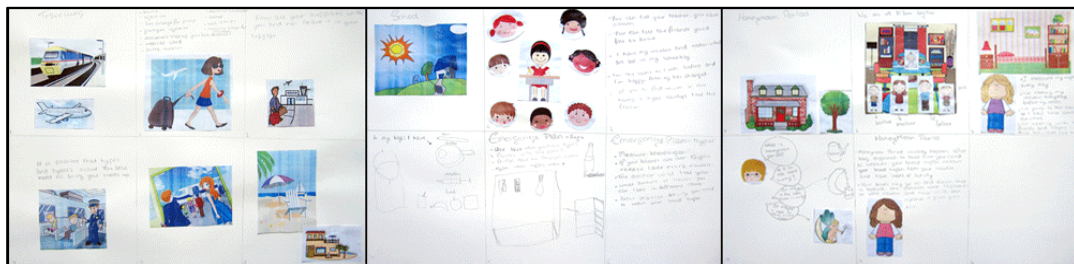

Figure 1: First workshop

To bring children into the design process, 'having a dialogue' (Guha, Druin and Fails, 2012) in the second and third workshop sessions, fourteen healthy children played with two decks of cards (i.e. one for each session, Figure 2) and other craft materials (Table 1) to develop characters, images, dialogue, etc. for two stories.

[7] Imb

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Figure 2: Story telling cards and story starters

In the first story '*Traveling through the human body*', two children undertake a journey into the human body with an imaginary technology. Looking through the porthole, they were able to see different human organs and their function in the human body (Tsvyatkova and Storni, 2015). Eight children used plasticine to make figurines of a nice pink submarine, the two main characters Liam and Abbie and clay models of some human organs (e.g. lungs, heart, stomach and pancreas). They played with the created human organ figurines, describing their functions and identifying their place using an outline of the human body, and elaborated on the characters dialogue (Figure 3).

Figure 3: Second workshop: Travelling into the human body

In the second session six children were asked to develop a story "*Superhero is sick*" in which a Superhero meets a doctor seeking effective treatment. The treatment included taking medication on time, having a healthy diet and being physically active. Children developed two characters - superhero Anastasia and Doctor Jenny - and played out the patient-doctor dialogue. Also, young participants were encouraged to explain to the Superhero what healthy food is, describe a technology with medication reminders, and to motivate the Superhero to participate in sports (Figure 4) (Tsvyatkova and Storni, 2015).

Figure 4: Third workshop - Superhero is sick

Findings and discussions

In a previous work we have discussed the sensitiveness of the topic in this research and how this influenced the emotional state and further recruitment of children with T1DM in the next, more design oriented stages (Tsvyatkova and Storni, 2014a). Also, these phases were significantly affected by the correct selection of methods and materials that could encourage children with diabetes to participate in the design process and could be less emotional and stressful for them. Building personal stories using the collaborative storytelling method, the child was asked to elaborate on scenarios using art materials, explaining only her experience with diabetes at the time of diagnosis and afterwards at home. The young participant felt confident in giving clear details on using the insulin pump, reading the numbers on the glucometer, food categories and symptoms recognition related to hyper- or hypoglycaemia. A problem that arose in practice was the appearance of some feelings of sadness. The role of the designer was to notice the early signs of those states and react accordingly, giving small breaks or changing the topic for a while to help the child to overcome the emotions. Checking blood sugar levels and having snacks during the workshop were planned in advance - this helped to observe the use of the glucometer, work with the insulin pump and gain experience. During this co-design the need of child training to share feelings, skills, experience and thoughts was not observed. It is important to highlight that the partnership between young participants and researchers was essential to identify the main features and content that the eBook needs to support. Having only one young participant (at a time) can be seen as an advantage for successful user-designer communication and dealing with emerging situations during the design session.

In an attempt to learn about children's language, communication skills and cognitive abilities - as well as to generate more valuable data for the eBook design - we worked with healthy children as "informants". The art and craft materials for each workshop sessions were carefully chosen to work in a constructive way to prompt creative direction for collaborative fantasy storytelling, introducing the basic story concepts in a fun and kid-friendly way. We noticed that some children are more open and confident in sharing their ideas. The role of the designer was to encourage each child to feel free to participate through forming small groups of two children to develop one object using the modelling clay or to draw a character.

Problems and limitations

Children are emotionally sensitive towards diabetes and this was the reason for the small numbers of sick participants in the first co-design session (Tsvyatkova and Storni, 2014a). This problem was overcome by using a set of DP (Tsvyatkova and Storni, 2014b) earlier in the project. Interestingly,

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we found it was difficult to involve boys in the workshops; all participants in the co-design sessions were girls.

Future Work

We completed a paper prototyping workshop session with children having T1DM and then using all the data collected (e.g. interviews, design probes and workshop sessions), we produced two low-fidelity prototypes of two stories inspired by the generated materials: "Superhero has diabetes" and "What is type 1 diabetes?". For the prototypes' testing and evaluation stage, a series of workshop sessions are planned with children with T1DM, possibly improving and iterating the prototypes increasing their level of fidelity.

Conclusion

Design partnership with children with diabetes requires a sensitive and responsible approach. Our results emphasize the importance of selecting appropriate design tools helping to facilitate creative collaboration and developing positive strategies to deal with the children's emotional states during the session. Working with a small number of sick participants improved child-designer collaboration and the ability to cope with unexpected situations. The need to train the child to act as a designer was not necessary. Individual attention given to each child will help to increase their active participation during the design process.

Acknowledgement

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