

# Educational Interactive eBook for Newly Diagnosed Children with T1DM: Children's Role in Design

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**Abstract** — Some of the central concerns in technology development for healthcare interventions in Type 1 Diabetes Mellitus (T1DM) are how to involve young patients and their families in the design process and what methods, including art-based activities, would best facilitate a child expressing their innermost feelings when applying child-centered and participatory approaches. This paper describes a variety of art-based tools and methods (e.g. Cooperative Inquiry (CI) and Informant Design (ID)) used in the creative design processes for defining features and eliciting the content of the stories, plots, roles, characters, images, animations, languages, etc., that will inform the design of an educational interactive eBook for newly diagnosed children (aged 8-12 years) with T1DM. The articulation of design ideas through modeling plasticine figures, drawing and thinking aloud were generated and collected in three workshop sessions organized for diabetic and healthy children who had different roles in and contributions to the design process. Successfully collected data will be used to build a series of low fidelity paper based eBook prototypes.

**Keywords**-children; type 1 diabetes; educational technology; Informant Design and Cooperative Inquiry

## I. INTRODUCTION

Over the last few years, a growing body of literature demonstrated how patient education is a key factor in the support of diabetes self-management practices outside the attention of the medical expert [7, 11, 12]. More and more technologies are designed with the aim of improving patients' education and pediatric diabetes is no exception [3, 4, 5, 6]. There is however a lack of studies that discuss how the designed technology addresses the needs of the actual users, and how users could be involved in its design.

In this paper, we report on further developments of a project aimed at investigating pediatric diabetes self-management practices, and exploring the role of interactive technology in patient education [13]. We show how we focus on users (parents and children), and how we draw on a series of user-centered approaches (Design Probes (DP) [8], Cooperative Inquiry (CI) [1], and Informant Design (ID) [1, 9]) to involve them in the design process. The focus on the role of interactive technology in patient education is motivated by early findings in our study showing limitations in the educational materials available to support newly diagnosed 'families' that can only experience hospital education for a limited time [13]. These findings helped to identify a more specific area for the exploration of a design intervention. Mindful that patient education is a complex matter that cannot be reduced to a technological intervention; we decided to explore the idea of an educational eBook for newly diagnosed children (between the

ages of 8-12) that children and their parents may use in the clinic and at home [13]. This eBook will be used as a tool helping to understand the role of technology in diabetes care as well as to examine users' role in design process.

In order to engage with users in a gentle way, learn more about everyday issues related with pediatric diabetes care and to collect design requirements and inspiration for the design, a series of DPs for children and their parents were developed and distributed [14]. While these tools will help gain a better understanding of the role of interactive technology in pediatric diabetes education, its development is exposed to reflection [10] to better understand the role of this particular type of user in the design process. To this end, this paper discusses the design phase of the eBook that follows our early investigations [13] and design probes [14]. In particular we focus on: 1) the methods and materials that we used to engage a group of children (one diabetic and fourteen healthy children) as active creators of stories highlighting their dual role as design partners (e.g. CI) and as informants (e.g. ID), 2), their particular contribution in the collaborative design process and 3) what (and how) collected materials were used to identify technology requirements. Three design workshop sessions were carried out to stimulate children's creativity and imagination in order to explore and generate a variety of narratives to inform the development of a series of prototypes of our educational eBook. In an attempt to gain some insight into the impact of diabetes on daily life, the first session was undertaken to develop scenarios to explore self-care practices carried out by young diabetics in clinical settings and in real-world environments. In this session the child's role was as an *expert*, qualified by her experience formed through living with diabetes. This helped to specify both the information that users need, and some of the features that this design intervention needs to implement. Later, some of the generated data was used in a second and third design session with healthy children. In these two sessions, the children's role was as an *expert* on 'being a healthy child'. Together with the children-informants the contents of two stories were developed - 'Traveling through the human body' and 'Superhero is sick' - including their plots, roles, characters, images, dialogue, etc. Art and craft materials together with two story telling sets of cards proved to be useful tools in inspiring the children's imagination, creativeness, and collaboration in fantasy plays.

## II. T1DM AND PRESENT EDUCATIONAL TECHNOLOGY

T1DM is a lifelong insulin-dependent chronic condition in which treatment requires learning and the development of special skills for daily care and demands extra attention when

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the patients are children [11]. As type 1 Diabetes Mellitus becomes more prevalent in young individuals<sup>1</sup>, new challenges in the delivery of health care and self-care education have emerged [7]. Children usually start their diabetes education soon after diagnosis [7], where they are encouraged to learn how to keep their blood glucose levels under control (testing blood sugar with glucometers), to inject insulin using syringes or pens, to understand carbohydrates and insulin dose adjustment, to detect and treat hypo- and hyperglycemia (symptoms presenting episodes of low and high blood glucose levels) and to partake in physical activities which affect their body's glucose absorption [12]. Day-to-day care can be described as an evolutionary process in which knowledge acquisition strongly depends on the physical maturation, psychosocial and cognitive growth presented by young individuals [11], combined with medical professionals, social services, parents, family and the school working together to increase its success [7, 12].

Recent advances in ICT opened up new possibilities for diabetes self-management education. For example Lieberman (2012) pointed out 14 well-designed diabetes self-management video games that can enhance health-related learning and behavior change [6]. A persuasive technology that was developed by Byer contained a blood glucose meter Didget@ that could be connected to a Nintendo DS game system. For checking their blood glucose, children get points as rewards to unlock new levels of games which helped users to improve their monitoring behavior [4]. DiaBetNet is a game that works with a wearable device - a glucometer and a standard PDA where young users have a visual graph representation summarizing carbs consumption, glucose readings and activities per a day [5]. Nao is a personal humanoid robot developed to enhance diabetes education and knowledge by playing a quiz with a diabetic child [3]. However, most of these videogames for patients with diabetes are outdated [2] or are only prototypes [3, 5] and the need for new educational technology interventions that correspond to the current technology trends has emerged. To explore this space, we decided that the active participation of children (affected and healthy) was to the success of a technology.

### III. STUDY DESCRIPTION

#### A. Methods

In the attempt to tailor an educational technology to the appropriate age group (8-12 years) [13, 14], their capabilities, specific language and natural skills, so to facilitate children's participation in the design, we used CI [1] and ID [1, 9].

CI supported children's involvement as design partners for 'elaboration' in the technology development lifecycle [1] wherein ID children's contribution was as informants through 'having a dialogue' [1] providing inputs at different phases of the design process (Table 1). Collaborative storytelling was chosen as an activity for all three design workshop sessions as an appropriate interactive communication tool that, together with the young participants, would help to define technology features and generate ideas about narratives, characters, plots etc., crucial for the development of educational stories that resonate with the child's perspective and imagination.

<sup>1</sup> According to 'IDF Diabetes Atlas: sixth edition' more than 79100 children globally under age of 15 were newly diagnosed with T1DM in 2013.

TABLE 1. DESIGN METHODS, MATERIALS AND PARTICIPANTS

Session	Design method	Materials	Participants
One	CI	A2 white paper, colored 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, A4 white paper, images, colored pencils	Six healthy children aged 11-12 years

#### B. Participants

Diabetes is an emotionally sensitive and difficult topic for discussion and having context-sensitive prompts in the session can provoke negative emotions among young participants or they may become upset [13, 14]. In the first session we worked with one 12 year old diabetic child who was happy to share her personal experience. The first small workshop session was held in a meeting room in a University Building. We had two reasons to involve healthy children in the subsequent workshop sessions two and three. The educational eBook is for newly diagnosed children who would not be familiar with diabetes, its causes and treatment but they will have specific knowledge and experiences accumulated during their childhood and their development within the school system. The first reason was to find out what un-diagnosed children think about the body, as this will likely be similar to what diagnosed children know about the body immediately after their diagnosis. The second reason was to know more about children's language, creativity, communication skills, interaction with the environment, their cognitive abilities and problem solving skills. Fourteen participants between 11 and 12 years of age (Table 1) were recruited from the voluntary group 'Sunflowers'<sup>2</sup> and the workshop sessions were conducted in their community centre, where other activities organized by the group were usually hosted. Estimated duration to complete each session was between 45 minutes and one hour in length.

#### C. Materials



FIG. 1. STORY TELLING CARDS AND STORY STARTERS

For the first workshop session, sheets of white A2 paper and art materials (colored pencils) were used to promote creative choices of writing and drawing, and selected images were used to support participants in the elaboration process to shape their own ideas. To encourage storytelling play in children for the second and third sessions, two storytelling kits (Fig. 1) were developed. Colorfully illustrated and left intriguingly open-ended, the storytelling picture cards were designed to engage young participants directly with the story, stimulating them to present their own concepts in a collaborative way. Together with the picture cards, the story starters were also designed to provide guidance and give some hints in developing specific characters/objects, settings or dialogues for the story. Each set of cards had seven story starters (i.e. questions) respectively corresponding to one or two picture cards. In addition to the storytelling card decks,

<sup>2</sup> Voluntary group of Russian-speaking parents and their bilingual children.

other materials to inspire a creative approach such as plasticine, a foam outline of the human body, pipe cleaners, buttons and feathers were provided for the second session, while in the third session children were given A4 white paper, images, colored pencils, dialogue boxes and glue to play with and expand their imagination (Table 1).

#### IV. DESIGN WORKSHOP SESSIONS

##### A. Session one

Applying CI and participatory design approaches, a 12 year old diabetic child and her parent participated as design partners. Together with the designer they cooperatively built up a wide variety of scenario stories where the action takes place in different settings e.g. at hospital, at home, at the shop, at school, etc., trying to highlight how diabetes and its management impacted the daily life of the young individual and their family (Fig. 2). In one of the scenarios, participants described their own feelings and problems experienced on the first day of diagnosis at the hospital as well as what questions and emotions arose and their efforts to understand more about the disease and its treatment.



FIG. 2. MATERIALS PRODUCED IN THE FIRST SESSION

Other interesting situations were related, such as how to buy healthy food in a shop, what is the honeymoon period for diabetes, what may happen at school when the child presents with the different symptoms of hyper- or hypoglycemia, and what is important for undertaking a journey. The last scenario was on the story of ‘Hypo-Hyper Man’ [14] in which the superhero<sup>3</sup> is a scientist dedicated to his work of finding a cure for diabetes. During the day in his Science Laboratory he conducts a range of experiments trying to find a new medicine to cure all people with diabetes and, late at night, uses a special technology having insulin and glucose for treating hypo- or hyperglycemia when children sleep. The original version of the story was developed by the same child working with DP materials and during the workshop session the fairy tale was fully implemented by her adding more details. Later, all the collected materials generated in the workshop were analyzed to identify features, images, text and contexts that could be implemented in the design of an educational eBook that would resonate with the actual users. This exercise also helped to identify subject areas that are of interest to the child e.g. to know more about the nature of diabetes, their digestive system and the relationship between food, insulin and physical activities. The next two design sessions were planned to cover these demands in collaboration with healthy children.

##### B. Session two: ‘Traveling through the human body’

In the second workshop session, eight healthy children played with a set of storytelling cards specially developed for the story ‘Traveling through the human body’ as informants (e.g. ID). The story is about two children who decide to make a

journey into the human body. Traveling in a miniature submarine, they were able to observe what different human organs look like and to examine their function. The set of 14 cards, together with other provided materials (Table 1), helped the children explain the key story elements gradually, adding details working with images and questions. The purpose of the foam outline of the human body was to help children explore different possibilities in the fantasy play and to rearrange the figurines of human organs, trying to find their appropriate place in the frame. Children were encouraged to describe their ideas about the journey by creating plasticine figurines of the lungs, heart, stomach and pancreas (Fig. 3). They also made the story characters Liam and Abbie and built a small pink submarine decorated with pipe cleaners, buttons and feathers. Playing with the modeled objects and performing dialogue between characters, they suggested that the journey should start in the mouth. Children were able to give some examples of how the heart and lungs work, what happens when the food reaches the stomach, but none of them knew about the pancreas’ position or function in the human body.



FIG. 3. TRAVELING THROUGH HUMAN BODY

##### C. Session three: ‘Superhero is sick’

Six children participated in the third session, trying to expand the story of a Superhero who was sick and meets the doctor to get appropriate treatment. Then the doctor explained to the Superhero that eating healthy food, taking medication and regular exercise would help in restoring his health. Children were asked to elaborate, describe and draw two main characters - the superhero and the doctor - using the provided art materials (Table 1) and the second storytelling card set.



FIG. 4. SUPERHERO IS SICK

Named Anastasia by the children, the imagined superhero was a 14 year old superwoman that could fly. She lives in a fancy apartment located in the city centre. Doctor Jenny was a very smart and popular doctor who cares for patients in the hospital (Fig. 4). Having played out the patient-doctor dialogue, Superwoman was advised to take her medication on time, to have a healthy diet and to partake in regular physical activities. Children were asked to explain to superwoman about healthy eating by selecting food items (from provided food images) and placing them in two categories, healthy and unhealthy, and then to describe what was the criteria for their classifications. Young participants were encouraged to choose a device that will remind Superwoman to take her medication on time. The technology proposed by the children was a smart belt that has an alarm, a note and a Wi-Fi enabled connection with other Superheroes. Finally, children were asked to motivate Anastasia to do exercises and some of the suggestions were to play a sport with friends, as physical activities would help her to be healthy and then she could fly to save people’s lives.

<sup>3</sup> One of the activities in the DP was to develop a story for superhero that has the power to help other children with T1DM.

## V. DISCUSSION

Having children involved in the design process as design partners and as informants was a successful approach in collecting and combining ideas and experiences from sick and healthy children which would inform the design of future educational technology. The first design workshop session in which the participant was *expert* in living with diabetes was crucial in discerning what information and knowledge the eBook needs to provide to help children and their parents learn about diabetes after diagnosis, and support them in diabetes self-care management when they return home. For example, children would like to know about the pancreas, insulin and their functions in the digestive system, and presenting this in a more playful manner may reduce the level of stress and anxiety associated with hospital stays. Having funny, yet sophisticated stories related to diabetes could help children to regulate their emotions and to reduce the pressure that they may experience in accepting diagnosis and its treatment. Integration of videos/animations in the eBook showing - in detail - some of the diabetes self-management tasks, games related to food and carbohydrate counting, and a small thesaurus with images and animation could help children to gradually learn about terminology and diabetes treatment, starting with their clinical education and continuing in a domestic environment.

Storytelling cards, in combination with other materials used in the design process, were a wonderful technique that afforded lots of fun, inspiring children to develop their own stories, and to use art materials when they were building their ideas. Having concrete questions revolving around the particular personas we developed, (as opposed to generic and abstract questions), helped to spur the young participant's imagination and creativity, to generate focused ideas from the children. Using the outline of the human body and objects of human organs made by children in the second workshop helped young participants, in a playful way, to show and test their story, and to generate data important for designers. The contribution of healthy children as informants in the second and third session was significant for the device development. For example, healthy children know little about the pancreas and its function in the digestive system, but they were very confident about the heart and lungs. This definitely confirms the usefulness of a fairy tale about the human body and digestive system that includes the insulin role and the process of converting food into energy. In the third session, children were inspired to elaborate on the dialogue between doctor and patient, asking the questions that each child may have when they are sick. They were confident in dividing food into healthy and unhealthy groups, but struggled with identifying the reasons behind food categorization. The second collaborative storytelling kit 'Superhero is sick' was used again in the prototyping session with children with T1DM, helping them to build a series of low-tech paper prototypes for the eBook.

## VI. PROBLEMS AND LIMITATIONS

Due to the emotional difficulties for children associated with their illness, the first workshop session was limited by the small number of participants. To deal with these constraints the DP [14] method was applied earlier. Also, several issues were detected while engaging children in the design process. Limiting the number of activities and questions offered more time for the children to engage with the contents and to lead the discussion.

Using modeling clay to make figurines and adding details is a time-consuming process and this problem was overcome by forming small groups of children to develop one object. Based on observation, the duration of workshop sessions should be no more than 45min as the children get tired and lose interest.

## VII. CONCLUSION

Trying to collect materials for the implementation and design of an educational eBook for newly diagnosed children with T1DM, three design workshops sessions were conducted in which children had different roles: as an *expert* in having diabetes and an *expert* in being a child. Young participants – both healthy and diabetic children - were encouraged to generate a sequence of scenarios through building characters, plots and settings in the storylines that will be used for low fidelity technology prototyping. The combination of art materials with storytelling card sets created a fun atmosphere, and encouraging children's responses in developing their own stories used in the sessions were effective methods in facilitating communication and data collection. In the completed sessions it was observed that healthy children are not familiar with the pancreas' function and knew very little about healthy and unhealthy food; they were not able to explain the criteria requirements for these two categories.

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