Adapting Design Probes to Explore Health Management Practices in Pediatric Type 1 Diabetes

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ABSTRACT
We used Design Probes (DP) as a communication tool supporting designers to learn about users, collecting self-documentation data from children and parents about their everyday chronic disease management. DP are also applied as alternative strategies to perform ethnographic study in a domestic environment and to elicit inspirational data for the design of an educational interactive eBook for newly diagnosed children with type 1 diabetes mellitus (T1DM). Eight probe activities were designed for children between the ages of 8-12 years who have diabetes and their caregivers, which were then distributed to seven families. The main issue discussed in this paper is the adaptation of the DP to the users (children and parents) and the results produced by participants who used them.

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

General Terms
Design

Keywords

1. INTRODUCTION
In this paper we report on our use of Design Probes (DP) to explore, familiarize and better understand young users’ needs, issues and perspectives regarding self-care practices in pediatric Type 1 Diabetes Mellitus (T1DM). The goal of this investigation is to inform the design and development of an educational interactive eBook for newly diagnosed children and their families. The development of the probes was informed by a series of exploratory semi-structured interviews conducted with parents/guardians who have experience with pediatric diabetes [8]. Through such explorations, we have identified a series of personal barriers, self-care needs, and difficulties in dealing with the disease on a daily basis often outside the attention of the medical team [8]. In particular, we found that affected families discussed negative emotions toward diabetes presented by their children and complained about the lack of a proper education and educational materials supporting newly diagnosed young individuals with T1DM [8]. Since this topic was recurrent, we decided to focus our attention on these educational issues as we explore the role of interactive eBooks in supporting better understanding and sense making.

Gaining first-hand experience of such issues is however very difficult: extensive ethnographic observations are difficult in domestic settings, especially in relation to such a sensitive topic; our interviews with parents were greatly informative, but children were reluctant to talk about their experience (parents were concerned that talking about diabetes was going to upset some of the children). Diabetes management is however constant and ubiquitous [7]; pediatric diabetes involves a series actors (parents, child, nurses, doctors and their perspectives) and different sites (home, school, playground, hospital, and their practices, etc). In the attempt to learn more about the perspective of the children, the practices in the home and inform/inspire our design intervention, we decided to develop some DPs.

We developed eight activities, supporting materials and instructions. Seven of these activities were intended for children aged 8 to 12 years who have T1DM and one was for their parents. Seven families used DP materials for a month and then the sets were collected and analyzed. In this paper we would like to report and reflect on the use of our probes. In particular we aim to show and explain how the DP materials were adapted to the peculiar target audience, and how the probes were used and appropriated by the children and their families.

2. DESIGN PROBES
DP can be seen as an unobtrusive way of collecting data, reducing the distance that separates the designer from the domestic settings they are designing for, especially in sensitive settings [1]. DPs include materials supporting self-documentation and a series of activities (physical objects and tasks) encouraging creative and subjective responses by the users that help with representing their own experience, daily lives, needs, and attitudes [2][5]. The set with designed objects is distributed to participants for a period of time and then returned to researchers. As often discussed [10], the goal is not to establish facts about diabetes, but rather to develop an understanding of their perspective so that our design would better relate and resonate with the user’s actions, intentions, emotions and environment [5].

Design probes were originally introduced as cultural probes by Gaver and colleagues [2]. In its original formulation, probes were a way to express the growing skepticism toward the rational(ist) method to collect design requirements, and to explore new tools that would trigger subjective and creative responses rather than objective and universal ones. In order to design innovative technologies for the elderly, the original packs by Gaver et al [2] offered a range of materials (postcards, map, disposable camera and photo album) to freely document the daily life of the elderly.

Probes were intentionally designed to elicit ideas and inspirations in researchers [2]. Mattelmäki [5] who worked extensively on design probes from the tradition of Participatory Design (PD),
pointed out that DPs “are an approach of user-centred design for understanding human phenomena and exploring design opportunities”. She emphasized three characteristics of DPs as an approach to User Centered Design (UCD). DPs support user participation by self-documentation (e.g. support PD). They focused attention on the users as they examined their personal context and environment (e.g. user’s work places, homes, hostels, sensitive care settings, etc.). DP’s exploratory character supports creativity and interpretation by users and designers [5].

There are only a few examples [4, 6, 9] of educationally-focused design probe studies for children, and in two of these cases children assisted in the development of the probe materials, objects and activities [6, 9]. In the design stage of game development, Moser et al [6] mixed qualitative and quantitative probe materials to collect data “to capture experiences” with games. The purpose of qualitative materials (e.g. postcards, collage and maps) was to explore children’s game interests, gaming behaviors and requirements, while the quantitative material (e.g. diary) helped designers to create child personas for different mini-games [6]. Wyeth and Diercke [9] used PD in a school environment to design educational activities for children between 11 and 13 years of age. The aim was to gain insights and inspirations for children’s educational software [9]. Nokia 7650 mobile phones were used as a digital cultural probe for collecting photos and audio clips by children to share their home life and after-school activities, and to design technology supporting education in the real-world outside classroom settings [4].

3. DESIGN AND RESPONSES

We adapted our packets of design objects into sets with an awareness of the children’s personality and maturation as well as the different stages of their cognitive and physical development [3]. As mentioned, parents shared valuable data related to the life of their children, their struggles, their activities at home and at school, information related to educational practices at clinic and domestic settings, and so on [8]. By analyzing this collected data we assumed that a design of an eBook may help parents and newly diagnosed children in their diabetes education as the technology can be used in both the clinic and home settings [8]. The data also helped us to devise and select the activities in the set of probes.

Seven probes were designed for children between 8 and 12 years of age, and one for their parents. For each probe, a large colorful box was used for the materials, labels and instructions (clear and expressed in a child-appropriate language suitable for the age-group). All activities in the probe set were understandable for children used to having pre-structured materials. The aim was to encourage children’s creative thinking and to help them to express their unique interests and needs, to document their own self-care practices, feelings and experiences with diabetes.

Below we describe the intended purpose of using each probe material, how they were adapted as well as some examples of generated data.

3.1 Disposable camera

For this activity we had a disposable camera, a series of sticky labels with numbers (1 to 22) and a list with 22 picture requests for the children (Figure 1, first image). The purpose of this probe was to learn more about the children’s point of interests, how diabetes influenced different daily activities e.g. sports, visiting places, meeting with people, playing outside with friends, things that they like or dislike, such as books, food, toys, etc. The second image (Figure 1) is a picture of an animated/cartoon movie that participant 2 enjoys watching. The third image is picture of a toy that the child (participant 1) doesn’t like. Knowing more about children’s preferences will help us to develop story characters and content for the eBook. Unfortunately, many photographs were of poor quality because of the children’s inexperience with the use of disposable (not digital) cameras. For instance, even with the clear instructions many had problems in activating the flash (key for taking pictures indoors), moving the advance wheel to wind forward to the next picture, and to determine the distance between the object and camera (disposable cameras have no screen).

Figure 1: Disposable camera with examples of responses

3.2 Technology Gadget Design

In this activity, children were asked to design a technological gadget that could help them in their daily life. Safe art and craft materials as pipe cleaners (regular and short), buttons, beads, feathers and foam blocks (Figure 2, first image) allowed children to explore their creativity and imagination whilst developing solid objects. This activity was particularly appreciated and seen as fun. Children produced their own concepts explaining the functions of their gadget, how it can be used, and what it would do. The concrete objects that were developed were: a non-invasive glucometer-bracelet (glucometer is a devise for measuring blood glucose level) (Figure 2, second image) and a combination of a glucometer and an insulin pump (a medical device that constantly delivers insulin to the body) (Figure 2, third and fourth images). The glucometer takes data from the blood and sends it to the pump for the automatic adjustment of insulin in the body.

Figure 2: Technology gadget design probe with responses

3.3 Send a Postcard

“My wife and myself share the care. ” (Parent 9)

“The only thing which bothers her was she never got to go to sleepovers...My mother lives in the north and she wants to stay there like sometimes in the summer and then maybe go on home. No problem but I can't leave her own, I didn't want to give my mum that responsibility.” (Parent 5)

Taking into account parents’ concerns about shared care responsibility in the family, we decided to use postcards as a tool to learn more about the children and their relationship with other family members, teachers, friends, relatives, etc. In the pack we had seven illustrated postcards with stamped envelopes, glue, a pack full of decorative material and a list with ‘common’ people (your doctor, your graney, your teacher, your cousin, your classmate, Santa Claus and us) to send the postcard to. Analysis shows that most of the postcards are addressed to children’s friends and only few to their relatives. Diabetes requires control and can be frightening for people who don’t know how to deal with T1DM in children. Sharing responsibility demands knowledge and practical skills in diabetes care in both children and the adults who will care for them.
3.4 Design Collage/Poster
This idea was taken from one parent who discussed how designing a poster for the World Diabetes Day positively changed the attitude and life of her daughter. Trying to provoke children’s interest and curiosity with the topic (diabetes), this probe contained art and craft materials (Figure 3, first image) that children used to develop their own collage/poster for an imaginary World Diabetes Day that they will present in class (Figure 3, second and third image).

Figure 3: Design collage/poster probe with some responses
Wyeth and Diercke [9] also used a collage in their DP pack but they didn’t get any responses from the young users. Contrary to that experience, we observed that designing a poster/collage for the World Diabetes Day was one of the favorite activities for children who participated in this study (Table 1). All children used the poster to explain technologies used in diabetes management (glucometers, injections, and insulin pumps), famous people with diabetes, and facts about diabetes and some of their feelings. This helped the children to articulate what they would like others to know about their diabetes; they seek out “positive role models” as an example of how they can achieve their dreams despite diabetes.

3.5 Kid’s diary

Figure 4: Kids diary probe with examples of responses
Trying to escape the tedious and boring activity of diary writing (we found that traditional method of keeping diary keeping is not motivating enough [9]) so we devised a graphical diary to provoke comments and reflections about self-monitoring and autonomy in children. We designed a template called “circle of activities” with five sectors. For each sector, we had a deck of available images that the children could use to stick on the segment appropriate to their activity (Figure 4, first image). The goal was to characterize diabetes related events (e.g. an accident) based on the five sectors: place when the event occurred, people who participated in that event, physical activity related to the event, used tools, and feelings. For example, they can use the image of a pump or of an insulin pen to describe the tool they used to inject insulin; they can use the image of a home or school to show the place where the insulin was taken. For participation or help, they were provided with the images of teacher, parent, etc. We also used different images related to sports and physical activities linked with the event in question, and finally for the feelings segment, we gave to them images representing hunger, dry skin, drowsiness, etc. A pack with small faces (ranging from sad to smiling) was also provided to help characterize the emotional state attached to that particular event. Children were also invited to decorate the diary and write supportive or other information they wish to share (Figure 4, second and third images). Only two participants used this activity. We found that the emotional state corresponds to the children’s problems with low or high glucose levels in the blood. Children detect some of the symptoms related to their state and gave explanation for this reason “…for my birthday I ate some sweets and my blood went a bit high…” (Figure 4, second image).

3.6 Super Hero and a story of his/her power
Children were asked to use modelling clay to model a figurine of a Super Hero who will help and support them in diabetes management. To help them to develop the character and to write a story for the superhero, we provided them with a series of questions (Figure 5, first image) regarding the name of the hero, his/her work and power, and how does superhero help all children with diabetes.

Figure 5: Super Hero probe with some responses
The aim of this activity was to get inspiration and hopefully develop one of the characters in the interactive educational eBook that we have in mind. Four children modeled a figurine of their superhero and answered the questions. Produced results were extremely rich. One of the stories described “Hypo-Hyper Man” as a scientist. During the day he is trying to find a cure for diabetes and by the night he is protecting children who are having high or low blood glucose levels.

3.7 Design your own recipe book

Figure 6: Design your own recipe book probe with responses
Parents struggle with managing the child diet (especially avoiding sugar and balancing carbohydrate intake). As reaffirmed in the exploratory interviews with parents [8], diet is one of the most difficult parts of diabetes management. Some of the parents use recipe books to help them with the ingredients and with counting carbohydrates (a key factor in a diabetes diet as carbohydrates are broken down into sugar by the body). With this probe we gave an opportunity for children to design their own recipe book (Figure 6, second and third images) as the collected data will help to develop interactive game elements in the eBook for healthy food. The book had four dividers for breakfast, lunch, dinner and snacks, and a nice recipe template to be filled (Figure 6, first image). Unfortunately, only one child worked with this activity sharing her recipes.

3.8 My problem solving diary
Parents are very busy, working very hard to manage the activities of their family and constantly care for their diabetic child. We had only one activity for the parents and this was aimed at collecting stories about emerging problems and how they are dealt with. In the diary each page has five sections (Figure 7, first image) as parents were asked to write their own concerns about diabetes care, feelings, emotional reactions, personal control of the situation, steps they take in solving identified problems, and lessons learned (Figure 7, second, third and fourth image). The parent’s diary gave rich examples of the constant stress provoked
by different issues related to the health of their children; struggles to make the right decision and lessons learned dealing with the problems. Most of the provided examples revolved around: sharing responsibilities with family members and institutions (schools and playschools), holiday traveling and diabetes, GP appointments, pump settings, high or low blood glucose levels, helplessness and tiredness described by parents trying to control diabetes.

Figure 7: My problem solving diary probe with responses

4. DISTRIBUTION AND REFLECTION

The recruitment of participants for our probes was performed among the parents who were already interviewed and who expressed their interest in continuing with this study. We had seven volunteering families, those parents who have children with diabetes between 8-12 years of age. After four weeks, a total of five boxes were returned. One of the authors met each volunteer to collect the sets and to learn how the materials and objects were used with a short follow up interview. All returned boxes with probes materials (Table 1) were analyzed with the aim to learn more about the young participants.

<table>
<thead>
<tr>
<th>Table 1: Responses</th>
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<tbody>
<tr>
<td><strong>Activity</strong></td>
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<tr>
<td>Disposable camera</td>
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<tr>
<td>Technology Gadget design</td>
</tr>
<tr>
<td>Send a Postcard</td>
</tr>
<tr>
<td>Design Collage-Poster</td>
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<tr>
<td>Kids diary</td>
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<tr>
<td>Super Hero and a story of his/her power</td>
</tr>
<tr>
<td>Design your own Recipe book</td>
</tr>
<tr>
<td>My problem solving diary</td>
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</tbody>
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According to Table 1, the design of a poster/collage about an imaginary world diabetes day is the favorite activity. The design of a Technological Gadget, the development of a Superhero and My problem solving diary were also pretty successful and generated lots of engagement. Children liked to work with materials to build their pieces with accurate features, but they had less interest in keeping diaries and designing their own recipe book. We can explain this lack of enthusiasm in using these materials because in diabetes management parents and children constantly keep a food journal and blood glucose log. Food restriction related to diabetes, the scheduling of meals and children's preferences cause parents constant concern about their children's diet.

This study suggests that applying the DP method is a promising way to collect data from children with chronic illnesses in private settings. Using DP we adapted objects and activities into sets for children who have type 1 diabetes to be appropriate to the children's ages, to be focused on young user's need (e.g. design your own Recipe Book), shared care with close relatives (e.g. send a postcard), their individuality (e.g. disposable camera) and experiences in self-care management (e.g. kid’s diary, super hero and a story of his/her power, technology gadget design and design collage/poster). Our materials were playful and intriguing, provoking a dialogue between designer and users, easy to use, having detailed descriptions and clear instructions, affording user’s involvement and participation in the design process. DPs helped to foster children’s imagination and, in some cases, to increase their willingness to describe and discuss the world from their perspective, despite their negative feelings toward the illness.

5. LIMITATIONS AND FUTURE WORK

The collection of the probe materials was a problem; it took a few months to arrange a time to meet parents. We found one limitation related to the amount of activities in the probe set. Eight activities for a month were a little ambitious assuming that parents did not have the time to help and encourage children to use the materials. Our analysis of the DPs results highlighted the success of the idea of a Superhero, which is currently the focus of a series of design workshops for diabetic and healthy children entitled “Superhero is sick”. Here children-generated scenarios are explored to fine-tune the language and narratives to be developed in our design. DPs further suggested the integration of game elements as well as the inclusion of references to real famous people who have diabetes.

6. CONCLUSION

In this paper we report on the use of design probes to explore pediatric diabetes management with children between 8 and 12 years of age. The main part of this paper concerns outlining our probes and how the participants used them. The reason for choosing DPs was to gain insights about everyday activities in non-clinically controlled settings (e.g. school, home and other domestic environment) but also and more importantly the subjective and creative responses of the affected children with the hope to develop a perspective, a language and an orientation for our design. The valuable knowledge obtained in this study will be used for the next stage of UCD, to elaborate design ideas for low fidelity prototypes to be tested.

7. ACKNOWLEDGMENTS

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8. REFERENCES


