

Research Article

Development of a Programme for Web-Based Support for Children – A Participatory Design in Children and Families with Urinary Tract Disorders

Margaretha Jenholt Nolbris^{1-3*}, Agneta Simeonsdotter Svensson^{2,4}, Gundela Holmdahl⁵ and Anna-Lena Hellström^{1,2,5}

¹Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden

²Centre for Person-Centred Care (GPCC), University of Gothenburg, Sweden

³Centrum for Children's Right to Health, Queen Silvia Children's Hospital, Sweden

⁴Department of Education, Communication and Learning, University of Gothenburg, Sweden

⁵Section of Pediatric Urology, Queen Silvia Children's Hospital, Sweden

***Corresponding author**

Margaretha Jenholt Nolbris, Institute of Health and Care Sciences, Sahlgrenska Academy, University of Gothenburg Box 457, SE 405 30 Gothenburg, Sweden, Tel: 46766186006; Fax: 4631786 6050; Email: margaretha.nolbris@fhs.gu.se

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- Web-based support

Abstract

Introduction: Children with urinary tract and bowel malformation often realize that they do not have the same body and genital appearance as their schoolmates. This sensitive matter affects their integrity, a private problem that not is discussed in public. It is a lack of prevention program, particularly developed in cooperation with the children. The goal with the present project was to get tools for support in daily live.

Aim: The aim of the study was together with the children, family, hospital staff and researcher; develop a web-based support program to be used in home setting.

Material and method: The study was conducted between 2011 and 2015. A participatory design was employed following the approach in person centred care with a partnership between 22 children 3-7 years old, their families and the research group of 8 persons. The program was built on stories about two children, their actions in different situations and with images to support the stories. Open conversations were used for the data collection and data were analysed using qualitative content analysis.

Results and conclusions: Steps of 8 themes were formed from the developing of the web-based program, which offered a user-friendly support in daily life for the children with long-term illnesses and family.

ABBREVIATIONS

WBP: Web-Based Programme; PCC: Persons Centered Care; UGM: Urogenital Malformation; UTI rec: Urinary Tract Recurrences

INTRODUCTION

Children in pre-schools, schools and in families are introduced early to technology for learning purposes as well as for pleasure. Children download games and search Internet for information and become accustomed to using computers, cellphones and tablets.

Computers programme can be a help [1-3] for children living with long term illness.

The own families usually represent comfort and security for a child but when they become old enough for school being like the others is important to feel well. A number of articles have been published confirming this phenomenon in children living with urinary malformation [4-8]. Strengthening the child's health and wellbeing in daily life a web-based person centered programme has been developed and reported the first to use SKYPE for conversations with preschool children [2,3,9]. The programme contains an element of active communication between a web

teacher and the child. The preliminary findings are promising and the SKYPE method appears to work with preschool children [2,3].

Person Centered Care (PCC), means that the focus is on the child as a person and not on the illness, making it possible to provide a more extensive richer care. PCC is based on patients' experiences regarding their own situation, individual conditions and resources with the goal of preserving their dignity [10-12]. PCC is also partnership, which includes power sharing. This entails a responsibility to involve the patient in the process and open the way reflective communication between participants [10,13]. The corner stones, apart from communication, are the child's own story, resources, needs and documentation.

The present intervention has now ending the developing phase. The design and content of the intervention is meant to be helpful for both the child and the family. In order to reach this it has been a necessary to involve not only the family and the child in the process, but also the doctors and urotherapists responsible for the care of these patients.

MATERIALS AND METHODS

A participatory design influenced by person centered care (PCC) has been chosen as the method for describing the process of developing the intervention in conjunction with a project management group and participating children and parents. The method is built on communication between the participants in accordance once with the rules of PCC.

In this method suggestions and opinions are taken into consideration and attempts are made to follow up them in order to adjust, in this case, the intervention according to the principle of participation in democratic decision-making and to access the knowledge the participants possess [14,15]. This method supports the UN Convention on the Rights of the Child [16] where children should be involved in of decisions themselves affecting.

Project managements group

AHL, the principal investigator is a pediatric nurse, urotherapist and professor with experience of urotherapy in children with urinary bladder disturbances and malformation. ASS is a special education teacher and PhD with experience in preschool pedagogics. IPS is a professor of early childhood education. MJN is a pediatric nurse and PhD experienced in the use of support groups of siblings in oncology nursing. For the latter technical assistance was provided by IT developers/designers (AW, RI). An illustrator (GW) was included in the group in order to meet future needs for images and animations. A pediatric urologist, GH, was incorporated in the project group, for medical support.

Setting, children and parents

The children were recruited in the study by the urotherapists at the Children's Hospital. The parents were then contacted by phone and given further information by ALH after which, if they gave their informed consent both the parents and the children were included. None declined participation. Healthy children were recruited from daycare centers by ASS. Children and parents (Table) were included step by step as the process developed.

Ethical considerations

The Regional Ethics Review Board in Gothenburg approved the study. The ethical considerations were guided by, and adhere to the Helsinki Declaration [17]. Informed consent was obtained from the parents and the children, written from the parents and oral from the children oral. The study was conducted voluntarily; the parents and children knew they could withdraw their participation whenever they wished and that confidentiality was assured. All data are protected by professional secrecy, no unauthorized person has access to the material and no individual child or family can be identified.

RESULTS

The interventions development was stepwise and different participants were involved throughout the process. Table and Figure describe the planning and the performing process. The different steps occurred in parallel and sometimes the process moved backwards and forwards.

Each step was followed by analysis and discussion in the group and understanding all the participants' opinions. We tried to follow the participatory approach with reference to the knowledge, perception, requirements and needs of the participants [14,15].

Step 1

A story had to be established as a basis for communication between the child and the web teacher. Our suggestion was a story about two children, Max and Sara, who lived in different families. The children would be involved acting in various situations that might occur in everyday life. These situations, together with images to support the story, would be created. The themes of the first stories were relations and emotions related to integrity. We tried at all times to bear in mind the goal of the main study; i.e. to strengthen the everyday health and wellbeing of the child living with uro-genital malformation (epispadia, bladder exstrophy, posterior urethra valves with renal insufficiency and Hirschprung's disease). We all agreed that images were important in providing subject matters substance for discussion between the child and the web teacher. Our first images were made by a model originally created by one in the project group (MJN) given information to children with cancer [18]. This experience encouraged the group to use a similar model. A web designer (AW) provided technical support in arranging the images and adjusting the recorded voices to fit the manuscripts (MJN, ASS). The intervention was first presented on a laptop, not using the web. The contents were discussed, adjusted and tested several times within the project group. We attempted to meet the intention of a person-centered approach in a partnership according to the general goal and found that the communication between children, web teachers and parents facilitated this.

Step 2

The project group discussed and tested ideas for various themes and how they could interact with; Sara and Max's families, body functions, emotions/ feelings/senses.

The plan was to test firstly in healthy children and their families, and then in children with other urinary tract disease or

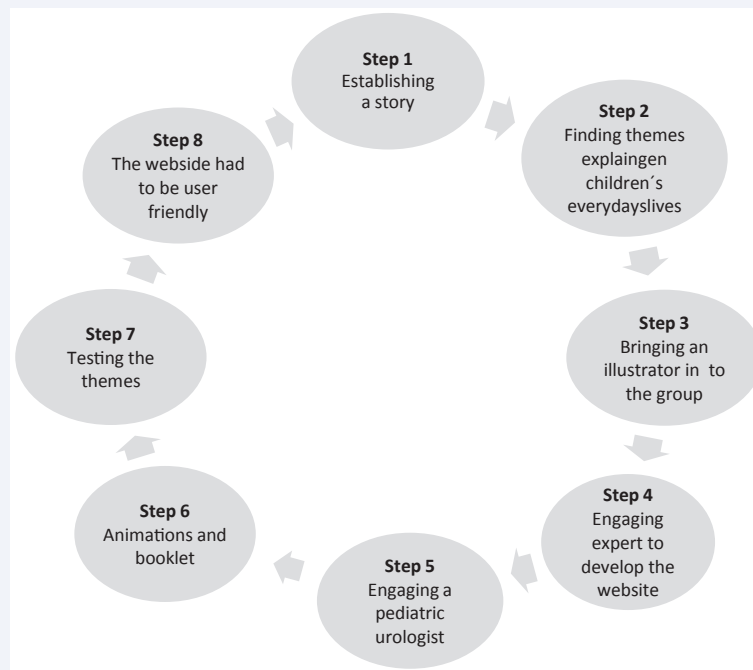


Figure 1 The eight steps.

malformation. In total participated 12 children with 8 mothers and 8 fathers in these tests (Table).

The theme's designated relations, was personified by Sara and Max's families and pre-school; that designated emotions/feelings/senses was represented by faces expressing different feelings. We also had some simple images made concerning the body.

Notes were taken during interviews with the children and their parents but the interaction between the interviewer and the child was also observed. The discussion was about color, shape and how they understood the story. They were also asked about what was missing and we got ideas about how to make improvements. The project group ASS, MJN, ALH discussed how the participants understood the story and images. The decision about how to continue was taken in the light of this analysis. However, we had serious problem creating attractive images despite our best effort to improve our knowledge. This lack of knowledge was holding the process back so we decided to find a professional illustrator.

Step 3

There was an urgent need to have easy access to an expert to cooperate with in developing useful illustrations for the stories. A professional illustrator was brought into the group (GW) and we were able to confer about what we wanted to illustrate rather than just has to use images that we were able to create. GW started to create good, useful images in Photoshop for presenting the body function, emotions/feelings/senses.

Step 4

The creation of the new and better images to support the themes of the stories, led us to believe that our ideas were mature

enough to be tested on the web. It was also time to recruit children with urogenital malformation to participate in developing the intervention.

Suitable images for the web now being available, a web-designer/developer (RI) was employed for the project, and the presentation on the web was discussed. We decided to use tablets rather than laptops to introduce the website. The tablet, iPad was chosen for the web platform, because it was frequently used in preschool settings, was considered easy to use and not fragile.

The ten children with a urological malformation and their parents began their inclusion in the study and the intervention was made available for them. The inclusion of patients in the main study had started and these participants were also included in the present study, showing how the intervention process was developed using a participatory design. From this stage onwards healthy children and children with urinary tract infections were no longer involved.

Step 5

The themes available on the website were the family relations, preschool relations, body functions, emotions, feelings and integrity. A theme including malformations was planned and the pediatric urologist responsible for the children's medical care was included in the research group (GH) to provide support. One theme was planned for each malformation was important to get relevant information and images that fitted with what could be used at the clinic.

In the theme aimed to explain the individual child's malformation in general, surgical procedures and treatment the urotherapist in the group (ALH) and the pediatric urologist (GH) worked on the story and images together with the illustrator (GW). The drafts were then presented on the web (RI), firstly for

Table 1: Participants and settings in each step.

Step	Professional	Setting child	Child	Parent
1	ALH, ASS, AW, IP, MJN	-----	-----	-----
2	ALH, ASS, AW, IP, MJN	Home	Boy 3y Healthy	Mother & father
2	ALH, ASS, AW, IP, MJN	Home	Boy 4y Healthy	Mother & father
2	ALH, ASS, AW, IP, MJN	Home	Boy 6y Healthy	Mother & father
2	ALH, ASS, AW, IP, MJN	Preschool	Boy 4 Healthy	-----
2	ALH, ASS, AW, IP, MJN	Preschool	Boy 4y Healthy	-----
2	ALH, ASS, AW, IP, MJN	Preschool	Boy 4y Healthy	-----
2	ALH, ASS, AW, IP, MJN	Preschool	Girl 5y Healthy	-----
2	ALH, ASS, AW, IP, MJN	Home	Girl 5y UTI rec.	Mother & father
2	ALH, ASS, AW, IP, MJN	Home	Girl 5y UTI rec.	Mother & father
2	ALH, ASS, AW, IP, MJN	Home	Girl 4y UTI rec.	Mother & father
2	ALH, ASS, AW, IP, MJN	Home	Girl 4y UTI rec.	Mother & father
2	ALH, ASS, AW, IP, MJN	Home	Girl 3y UTI rec	Mother & father
3	ALH, ASS, AW, MJN, GW	-----	-----	-----
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 7y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 6y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 6y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 7y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 5y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 4y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 6y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 4y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Girl 4y UGM	Mother & father
4	ALH, ASS, AW, IP, MJN, GW, RI	Home	Boy 3y UGM	Mother & father
5	ALH, ASS, AW, IP, MJN, GW, RI, GH	Home	10* Children UGM	Mother & father
6	ALH, ASS, AW, IP, MJN, GW, RI, GH	Home	10* Children UGM	Mother & father
7	ALH, ASS, AW, IP, MJN, GW, RI, GH	Home	10* Children UGM	Mother & father
8	ALH, ASS, AW, IP, MJN, GW, RI, GH	Home	10* Children UGM	Mother & father

comments from the project group ASS, MJN and secondly from the children and parents (Table).

Step 6

New images were required to fit the coming needs of the themes. There was a suggestion, that animation of some images might make the story more interesting and the possibility of having Max and Sara of the story in a paper version was considered valuable. New images and voices and animations were discussed in meetings and were also printed as booklet and sent by post to the child with the discussion of specific theme. This helped the children and web teacher in their communication via Skype, as they could communicate and see the images at the same time.

Step 7

All themes were available and used in the communication between the child and the web teacher via SKYPE. Evaluation of the intervention continued.

The themes were finally settled after consideration by ASS,

MJN, GW, RI, GH, ALH, the children and their parents, but new ideas were still welcomed.

Step 8

The design of the website was discussed again to ensure that it was as user-friendly as possible for the participants. The web layout was created and tested first between RI and GW and then by the children and parents. Technical features were developed and tested by RI to suit different systems. The website was made available for the children and parents with encoded access. The project group had similar access. Each theme was introduced with an image and each malformation theme was available exclusively to the individual child.

DISCUSSION

In creating an intervention that will be useful for children and families in everyday life, the family should be involved from the beginning. This paper presents the process through an example of the use of participatory design inspired by Spinuzzi [14]. The PCC approach focuses on the child's life in preschool and in the family and managing to deal with future situations that may

arise due to urinary tract disorders and how the children can use their own resources and retain their self-esteem [10,11,19]. Through the various steps the intervention is developed guided by ongoing communication in the group of participants. Developing a supportive intervention for younger children is special; you cannot expect the child to have words for feelings or experiences or to know about the healthy body. The intervention was justified by Article 12 in the UN Convention on the Rights of the Child (UNCRC), which highlights the child's right and their own perspective to express thoughts and will [16].

The focus of the communicative encounters varies, but whatever the theme, its scope or depth, the web teacher follows the intention of each activity, carefully listening to the child in order to support the message [2,3]. It is a didactic approach to children's emergent understanding of different aspects of the world around them and how they can be encouraged to participate, related to various situations and other people [20].

The content of the themes has been tested back and forth within the project group and new ideas arose about reorganizing and further developing the design. All the participants were able to reflect continuously during the development of the intervention, the story and the images. As concerns the participatory design, the focus was on user needs in the different steps, with the whole team working in co-operation.

The children and their parents gave feedback that helped with the understanding of the images and the textual information. Medical experts supported the intervention with valuable input about the children's urinary tract disorders and suggested interventions for each child. The web developer constructed the web page, presenting the themes and the images together connected with sound technical functions. The illustrator contributed expertise and great experience, creating attracted images and animations.

Skype was used in order to simplify things for small children, who find it difficult to reading and write. This method offered two-way communication using not only language but also gestures and facial expressions, which strengthened the dialogues with the children [3,21]. The result of this design seems to be a useful web intervention for children with urogenital malformation and the goal was achieved with to strengthen self-esteem and health in children with urogenital malformation and is meant to be offered to children of pre-school age [2,3]. The web-based programme offered support in daily life for the participants—children aged 3-7 years with urogenital malformation. The children were able to talk about what it has meant to them: Family environment, pets, knowledge about counting, reading and colors and own reflection of their disability, body and feelings [21].

CONCLUSION

The participatory design with children, parents, researchers, web designer and illustrator was suitable to use in developing a web-based support for children with uro-genital malformations. All participants participated actively in the various steps according to their own knowledge and experience, to development of the web site, images and texts. Children's experiences have contributed the most important part of the process, which was the construction of the website that would

help children to understand and reflect on different situations. Having a PCC approach illuminates that behind every child with an uro-genital malformations, is a child as a person. The benefits of the intervention can now be tested in a long-term study.

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