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Skype Support for Preschool Children with Long-Term Illness—One Year Follow-Up*

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Aims and objectives: The aim of the study was to evaluate support in daily life, in terms of one-year outcomes of a person-centered web-based programme. Background: Children with a chronic disease are at risk of ill health. In school they are vulnerable as they differ from the other children. The united nation convention on the rights of the child awards them rights concerning the promotion of their health and wellbeing. Design: Descriptive qualitative design. Methods: The study was conducted from 2014-2015. Open questions were used in Skype conversations between children and web teachers (a mean of 12 conversations per child). Data were analyzed using qualitative content analysis Results. The web-preschool was found to support the ability to understand, reflect, discuss and find tools dealing with different situations. Sense of coherence was important. The development of verbal and communication skills was clear. The programme included images, narration and two-way Skype communication between child and web-teacher with the possibility of offering flexible support depending on needs. Conclusion: The web-based programme offered support in daily life for the participants—children aged 3-7 years with long-term illnesses.

Keywords: children, health promotion, long-term illness, malformation, person-centered care, paediatric urology, Skype

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Introduction

Children with a chronic disease have rights aimed at promoting their wellbeing and health according to the United Nation Convention on the Rights of the Child (UN, 1989). Article 3 stresses that the child's best must come first in all decisions that affect them and Article 12 that children should be able to freely express their thoughts, be listened to and the child's perspective should always be taken into account.

For children with long-term illness, the family may represent comfort, security, act as advocates and protect the child from unnecessary suffering (Berntsson, Brydolf, Berg, & Hellström, 2007). This changes when they start school as the child then has to face problems without the help they are used to. This is a period of risk for children with ill health and reduced compliance with treatment (Berntsson et al., 2007; Ebert, Scheuering, Schott, & Roesch, 2005; Hellstrom, Berg, Sölsnes, Holmdahl, & Sillén, 2006; Holmdahl et al., 2007; Wilson, Pistrang, Woodhouse, & Christie, 2007).

Background

Children with urinary tract and bowel malformation (UTABM) may realize that they are not able to go to the toilet in the same way as their schoolmates or they do not have the same genital appearance. This is of a sensitive matter and affects their integrity, but it is traditionally a private problem, not discussed in public.

Gaining a sense of coherence (SOC) in this context is significant to feel healthy (Antonovsky, 1987) and may be a bridge to understanding sorrow and suffering. To achieve SOC, children with UTABM need access to tools that will allow them to accept what is different and focus on what is good in order to see what is comprehensible, manageable and meaningful from of their own perspective (Antonovsky, 1987). This conforms to the goal of person-centered care, where the child's own story, resources and wishes are the focus (Zoffmann, Harder, & Kirkevold, 2008).

Preventing ill health in adults using support via the internet has been presented as valuable measure by groups (Berg, Adolfsson, Ranerup, & Sparud-Lundin, 2013; Josefsson et al., 2013). Skype technology has been shown to be useful in web-based support for children who are unable to read and write and makes the child feel comfortable as they can participate from their own home (Hellström, Simeonsdotter Svensson, Pramling Samuelsson, & Jenholt Nolbris, 2012; Simeonsdotter Svensson, Pramling Samuelsson, Hellström, & Jenholt Nolbris, 2013). The current study was undertaken to investigate support in daily life to young children using a web-based programme.

Aim

The aim of the study was to evaluate support in daily life, in terms of one-year outcomes of a person-centered web-based programme.

Methods Design

The study was qualitative descriptive in design and data collected repeatedly in each child (Taylor & Bogdan, 1998). Open questions were used in conversations between children and web teachers (Dochery & Sandelowski, 1999). Skype was used to facilitate communication between the child and the web-teacher (Simeonsdotter Svensson et al., 2013).

The Web Programme

The web-preschool programme was an intervention offered as a platform, based on a narrative about two fictional children, Max and Sara. A voice-over told their story, illustrated by images. The goal of the programme was to prevent ill health in children with long-term disease by strengthening their self-esteem, wellbeing and health. Max and Sara appear in a variety of situations, linked to certain themes; family situations, preschool activities, spare time, relations, emotions, integrity, body functions, thoughts and the child-specific malformation.

A specific theme was pre-determined for discussion in each session and Max and Sara's story was discussed followed by the child's own experience of the theme. The child was encouraged to take an active part.

Support and follow-up questions that could advance the discussion were: What did you think? Can you tell me more? Can you explain more or why? The web teachers in the present study were MJN, a registered nurse who is specialized in pediatric nursing and ASS, a special education teacher. Images of the next planned theme were sending in forehand as paper copies by ordinary mailto the child's home. The intervention starts with an introduction and explanation of how to use the different parts, done in the child's home, affording the web teacher and the child the opportunity to get to know each other.

Participants

Ten children, nine boys and one girl, aged 3-7 with severe urinary tract and bowel malformations participated in the study, all recruited from the hospital.

Data Collection

The recorded conversation between children and web-teachers was collected from June 2012 to April 2015, (143 Skype-communications, and lasted between 3 and 22 minutes (mean 13)). The Skype-interviews were timed to allow the children to participate once a month. After each conversation the web teachers transcribed the interviews verbatim.

Analysis

A qualitative content analysis was used to draw a systematic conclusion and to extract the message from the text. This reliable text analysis technique is replicable and valid (Krippendorff, 2013). In the first step, the authors individually read the text to gain an impression of the whole arranged in time intervals. The second step was to identify meaning units in the text, which reflected the study aim. The text was then condensed, meaning units were coded and sorted into subcategories and categories. In the third step, the authors discussed the findings together until consensus was reached.

Ethical Considerations

Informed consent was obtained from both children (oral) and parents (oral and written). The families were informed that they could interrupt their participation at any time. Confidentiality was ensured and the Regional Ethical Committee for research has approved the project. All data material is protected by confidentiality and no unauthorized person has access to the data and no single child can be identified.

Results

The findings are presented in 2 categories with subcategories; getting to know phase and own reflections. The findings are presented with quotations, a number indicating each participating child and the letter W the web-teacher. The results are based on together 143 conversations, each child participated in mean in 12 conversations, range 11-17.

Getting to Know Phase

At the start the focus was on getting to know each other and becoming familiar with the technology. Stories and images about various relations and situations in the family and preschool setting were discussed.

Family environment. In this subcategory, the children talked about their own relatives. The web-teacher asked the child what they saw:

> "Tell me who you can see in the picture." (W)
> "I've got lots of cousins and four grandparents." (1)

The child could also start telling the web-teacher about the people in their vicinity.

> "I went with my cousins to the zoo and circuit racing with a ropeway." (2)

Pets. The story of Max and Sara includes pictures of pets and cuddly toys in the theme relations. The children told about their own pets but also that they wanted one.

> "Do you know any pets? Or perhaps do you have one at home?" (W)

In the Skype conversation, the children often used to show and explain different things and the children show their pets.

> "Here's my new kitten. She eats cat food and plays." (5)
> "Can I see the kitten?" (W)
> "Look, now she's playing." (5)
> "Wow, she's so clever." (W)
> "Yes, I've taught her all by myself." (5)

The children's terms of participation. The Skype conversation was on the children's conditions and the children could quickly end the conversation by just saying they wanted to stop for today and clicking off Skype.

> "Do you think we're finished for today?" (W)
> "I'm closing Skype I don't want to talk anymore." (3)

The children sometimes joked by hiding themselves or jumping in front of the camera.

> "Hello there." (W)
> "Now I can see you again." (6)

The child could also Skype with the web teacher when on vacation abroad.

> "But wherever are you" (W)?
> "I'm on the Canary Islands, I'm on holiday and I've got a lovely bracelet and I've been in a plane" (5).
> "It's great that you have Skyped me and told me that" (W).

Counting, reading and colors. After one month the children seemed to be comfortable with the Skype-conversation and proud talking to their web teachers. They used the pictures to express what they knew and could do, they counted things in the pictures and some could read the text.

> "Tell me what you can see." (W)
> "There are three cars and one, two, three, four, five, six birds, loads of trees and flats." (3)
> "Is there anything else?" (W)

> "And one, two, three, four, five animals there." (3)

The children liked to talk about what they had learned, and showed a lot of pride.

> "We've got math's books and lots of sums to do." (4)
> "Are you clever?" (W)
> "The teacher says I'm good at plus and minus." (4)
> "You've just shown me that." (W)
> "You know, I can count really well now, much better than before." (4)

The children liked to describe the colors of different things and say what colors they liked.

> "What have you got there?" (W)
> "Look, this hair band has glitter on it and gold, it glitters. It's gold and lovely. I have it on my plate." (9)
> "Do you have a jumper the same color as the children have in the picture?" (W)
> "I have a new red and blue jumper. Dad has the same jumper but his is only blue." (7)

The color black was used in a play situation to make fingerprints and explain that each person is unique.

> "Which picture would you like to talk about today?" (W)
> "Fingerprints and I put black felt pen on my finger and pressed." (8)
> "Do you have the same fingerprints as mum?" (W)
> "No, it tells you on the picture that everyone is different." (8)

Own Reflections

After a period the children were often able to discuss their thoughts and reflections. They had also learned a lot of useful words during the discussions in the web-preschool. They could talk about what they had seen in the pictures and stories and put it in another context. Three subcategories are presented below.

Disability. When the children saw the picture of the boy in the wheelchair, they expressed empathy and could imagine how it would be like to be in a similar situation.

> "There's someone in the fifth class who has a wheelchair, when she goes in there is a ramp that she goes upon. Otherwise it wouldn't be fair if she couldn't get in." (1)
> "What do you think?" (W)
> "It would be hard if I had to sit in a wheelchair and I would miss being able to play football." (1)

The body. The children talked about various aspects concerning the body, including the child's own malformation and they always tried to understand more by discussing things with their web-teacher. Their thoughts developed in to reflections and they now had words to tell and explain.

The children described for example, what it was like when they had to go to the bathroom and how it worked.

> "Here's a new picture and there's a button, I was sedated and they operated it in." (6)
> "Interesting, can you tell me more?" (W)
> "There's a picture of a tube and I wee with it when they put the tube in and when I've finished weeing I close the lid." (6)
> "How did you get the tube?" (W)
> "I had to be sedated and had a mask put on and it smelled strange." (6)

The children said they could need some help in bathroom at school.

> "Is there anything in the picture you recognize?" (W)

> "I got a thing like in the picture with my body, I got it at the hospital to wee and then the teacher at preschool helps me." (4)

Digestion was an exciting topic, and was described in detail.

> "What's she doing?" (W)
> "She's eating and she's eating …three milk drinks and then, through the arrows, it goes through her throat and comes out in the toilet and then the toilet roll and flush." (3)
> "What should you do after that?" (W)
> "Wash yourself." (3)
> "What else happens?" (W)
> "Wee comes out when you have drunk ever such a lot, enormous amounts. It's nasty to go to the toilet." (3)
> "Why is it nasty?" (W)
> "It just is." (3)

Blood was also an interesting subject, particularly for children who often had to have blood tests. They could show their finger to tell what has happened.

> "What have you done?" (W)
> "I was at the hospital and I was sad." (9)
> "Can you tell me more about it?" (W)
> "It hurt and I shouted 'Ouch!' She pricked my finger, here. Can you see?" (9)

Feelings. In the theme emotions, the children practiced recognizing emotions from a face scale. The children could describe different situations that led to the emotions they experienced. Being brave was a feeling they were proud of and they also liked to talk about situations where they had been brave.

> "Are you brave?" (W)
> "Yes and I looked like this after I'd been sedated, happy and brave." (6)
> "You dare to go up to an elk or something." (6)

The children had experiences of being angry and knew what it that looked like.

> "Can you find any face that looks angry?" (W)
> "Yes, here they are." (8)
> "When are you angry?" (W)
> "I was angry with grandma because she didn't have a cycle helmet when she cycled." (8)

Some days the children did not want to be at preschool, but they had to be there anyway. They said that these days they felt sad and longing their parents.

> "I am a bit sad." (1)
> "Why are you sad?" (W)
> "I really wanted my mum at preschool and I cried." (1)
> "That's no fun." (W)

The children could sometimes talk about friends not being nice to them at preschool.

> "I haven't played today at preschool. It was no fun, I wasn't allowed to be with the children." (7)
> "Why was that?" (W)
> "They do that sometimes and then I go to the teachers." (7)
> "That was a good thing to do but why do you think you weren't allowed to be with them?" (W)
> "They're stupid sometimes." (7)

> "But what do you do then, why are they stupid?" (W)
> "I think that I don't care so much about why." (7)

It was difficult for the children to talk about the future, as it was abstract and not easy to understand. They hoped that everything would be better and also that they would fully recover their health.

> "How do you think it will be with weeing later when you are bigger?" (W)
> "Anyway I can run and not wee so much. It's a nuisance with weeing. And not have one of these (diaper) then." (2)

Discussion

The intervention "person-centered web-based learning support" for preschool children with uro-genital or bowel malformations, where the goal is to prevent ill-health in school-age children, is the first of its kind. This is achieved by strengthening and maintaining self-esteem and wellbeing/health from an early age, rather than waiting until problems occur.

The present study investigated support provided by discussing situations in daily life that the child might, or already had, experienced. The discussions always started with the fictional stories about Max and Sara. The programme accords, in all respects, with the United Nations Convention on the Rights of the Child (UN, 1989). Sense of coherence in the present study was a bridge to understanding positive and negative feelings, body function and what the particular malformation means for it, and how to cope with future situations (Antonovsky, 1987). This also conforms to the goal of person-centered care, where the focus is the child's perspective.

The findings from the present study, so far, are positive and promising. Only a few of the participants had started school after one year so the long-term effects cannot yet be seen.

At the end of the study the children felt comfortable with the web teacher, had verbally developed their language with new words and communication skills. In another study about interaction with healthcare professionals, shows the importance for the child to be a part in the process and feeling trust (Sjöberg et al., 2015).

The age range was wide but, according to age, all had developed a lot. The youngest developed most, the Skype camera facilitated communication by allowing the use of body language and the possibility of showing what they wanted to talk about.

After one year they all could express themselves and discuss whatever they wanted. They could understand the meaning of emotions but still, had difficulties analyzing them. For example, they could end a discussion by saying "It just is like that". They could explain about their malformation and what it meant in terms of hospital visits, restrictions and efforts that have to be made. The children had an optimistic view of the future, were proud of themselves and an awareness of their own resources.

Web-based support was possible in this preschool population thanks to Skype, as we have reported in an earlier paper (Simeonsdotter Svensson et al., 2013). Based on the fictional stories and pictures, the children were able to tell about their relations at home, in school, their body, malformation and emotions. They could recognize situations from the pictures, put them into their own context and reflect over what happened in accordance with the process in which preschool children learn to think, reflect and communicate thoughts (Pramling Samuelsson & Asplund Carlsson, 2008; Sommer, Pramling Samuelsson, & Hundeide, 2010).

Verbal communication together with body language, made it easier for the web-teacher to understand the children better (Simeonsdotter Svensson et al., 2013).

The intervention presented has been developed together with children, families, professionals and is a first attempt to provide tools that will strengthen children when they start school. The method participatory design is described in earlier studies (Gregory, 2003; Spinuzzi, 2005). Spending time to develop trust in the getting to know one another phase was beneficial and a prerequisite for continuing the rest of the communication. This method is in agreement with Kortesluoma's description of how to interview children (Kortesluoma, Hentinen, & Nikkonen, 2003). After some months they develop communications skills, become aware of own resources and were proud and eager learn more in communication with their web-teacher.

Our findings confirm studies in learning and communication in preschool settings (Pramling Samuelsson & Asplund Carlsson, 2008; Simeonsdotter Svensson et al., 2013). Various kinds of relations were discussed in the web-preschool. To have good relations with friends was already important at preschool age and increased with time. The importance of having close friends has been shown in other studies in children with uro-genital disease and other long-tem illnesses (Hellstrom et al., 2006). Looking at pictures of the organs of the body helped them to understand their own body function. The malformation, treatment and checkups could be discussed. Pictures are often used today in intervention programs for children (Nilsson, Buchholz, & Thunberg, 2012; Nolbris, Abrahamsson, Hellström, Olofsson, & Enskär, 2010).

Face scale was used in the intervention to discuss emotions and feelings, first with reference to Max and Sara and then to the children's own experience. It was easy to recognize, related it to one's own situation and brought an understanding of the behavior of friends and others in their surroundings. They liked to talk about how brave they had been in different situations and showed pride in what they could do. They sometimes talked about other children not allowing them to take part in play. If that happened they went to the teacher and complained.

When talking about their malformation, as explained in the web-preschool, they showed recognition and started to explain about themselves. Toilet visits used to be sensitive and a problem in school for all children and particularly for those with urine and bowel problems (Lundblad, Hellström, & Berg, 2010). In the present study, only the oldest showed signs of uncertainty about it. The youngest felt confident in the help they received from teachers and had no problem with integrity.

The intervention evaluated tried to adapt to child's own situation and perspective according to children's rights (UN, 1989) and not just what parents or health care team think. The intention of the intervention was to follow the child's wishes and needs and attempt to strengthen their resources and health by communicating about this with their web-teacher. The children got tools to discuss matters of importance to them. Children like to share decision making in all situations, otherwise there is a risk of them losing control and their own integrity (Darcy, Knutsson, Huus, & Enskär, 2014). Arguments for taking the child's perspective need to be encouraged in healthcare (Nilsson et al., 2013).

It is positive to tell their own story and tell all about what was experienced in a specific context. It gives a meaning to what has happened and facilitates understanding and acceptance on the situation (Antonovsky, 1987). In the present study, the communication between the child and web teacher accorded with the sense of coherence (Antonovsky, 1987) person-centered care (Antonovsky, 1987; Ekman, 2015; Hellström et al., 2012; UN, 1989; Zoffmann et al., 2008) and children's right (UN, 1989).

Methodological Considerations

The study design chosen made it possible to evaluate the conversations between children and web teachers in such a way as to accord with the aim (Taylor & Bogdan, 1998). The validity of the findings was ensured by the significance of the recurring monthly conversations. The development could be followed in what was a known situation for the child who made them feel confident.

The web-based programme was created for preschool children but in our group one child had already started first grade, which may have affected the reliability. However, the aim was to evaluate support in daily life and the conversation level could be adapted to different ages and needs.

Conclusion

Children with uro-genital and bowel malformations, aged 3-7 years, are able to participate in a program consisting of person-centered, web-based support using communication via Skype. The support the children experienced can be expressed as an ability to understand, reflect, discuss and find tools to cope with different situations. Sense of coherence was important. Similar programmes can be used for most of children with long-term illnesses.

Relevance to Clinical Practice

This study shows that a web-based programme can already be used with preschool children to help them to find and strengthen their own resources, understand their rights, and acquire the tools they need to discuss matters that are important to them. In web conversations with a web teacher, children can understand, reflect, and find the tools they need in daily life, regardless of their geographical distance from a hospital.

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