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What constitutes the patient experience of children? Findings from the photo elicitation and the video diary study

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Abstract

Patient experience (PX) is getting attention among researchers and healthcare service providers, but little is known about the experiences of child patients and how to explore those. This paper reports findings from a study in which two participatory research methods, photo elicitation and video diary, were applied to investigate the elements of children's PX in the context of children's hospital. The aim was to find out what elements constitute the PX of children aged 7–16 years. The research data were gathered in 2016–2017. Twenty-two child patients participated in the study: eight children aged between 7 and 10 in the photo elicitation part, and fourteen children aged from 10 to 16 in the video diary part. In the analysis, the data were first analyzed per research method but afterwards combined and analyzed together. Based on the analysis, four main themes of PX of children were identified: 1) hospital facilities and entertainment, 2) medical care, 3) social relationships with the hospital personnel and other people, and 4) feelings and coping with the illness. Feedback on the research methods from the participated children was mainly positive. Further work is needed to validate the findings and introduce new creative approaches to research PX of children of different ages.

Keywords

Children, hospital, patient experience, pediatrics, photo elicitation method, teens, video diary method

Introduction

Engaging patients in the development of care services is fundamental when health care organizations strive to provide high quality services that are responsive to patients' needs.¹ Studies on patient experience (PX), which include the patient's perceptions across the whole patient journey, are increasingly published, but the perspectives of children have received little attention.^{2,3} There seem to be several reasons why researching the experiences of child patients and their participation in development activities in hospital are challenging. First, PX is an emerging concept. Researchers have suggested that PX is more than patient satisfaction alone and that PX contains the following aspects: continuum of care, focus on expectations, individualized care and alignment with patient-centered care principles.^{4,5} Moreover, it has been recognized that parts of experience that traditionally are not seen as related to health care have actually become interwoven as a patchwork to form something much greater.⁶ Second, in pediatrics, the constraints of the hospital context are substantially increased. According to Bishop,⁷ barriers to children's participation are formed because hospitals are constrained by several factors, such as organizational culture, skepticism toward qualitative research, access restrictions and ethical approvals. Bishop⁷ claims that the demanding nature of the health care context is one of the

reasons for the incomplete understanding of children's experiences of hospitalization.

To date, the value of children as informants of their own health seems to be poorly understood.⁸ For example, a study conducted in 2011 in Finland⁸ found that only 27% of child patients had been asked about their experiences of a health care visit. In the hospital context, children's rights⁹ have a special role. The European Association for Children in Hospital has established a charter¹⁰ to act as a guide for protecting the rights and well-being of sick children.

Some studies have explored the PX of children and teens in a hospital context. The studies have focused on experiences of hospitalization,¹¹⁻¹⁵ treatment of outpatients¹⁶ and home care.^{17,18} With regard to the findings from a PX viewpoint, the studies identified topics of fear and worry,¹¹ themes about the physical environment,^{13,16} the importance of communication and the relationship with health care personnel,¹⁶ the preference for home care,¹⁷ the four groups of pain experiences of children¹⁴ as well as how novel digital services for children and their families can improve the PX in a children's hospital.¹⁵

In Finland, the interest toward PX has increased along with the construction of a new children's hospital in the capital region.^{19,20} Special attention has been paid to investigating the perspectives of children and their families with regard to hospital visits, care and treatment as well as everyday life with an illness.

This paper aims to answer the following research question: *What elements constitute the PX of children between 7 and 16 years of age?* The paper presents findings from a study that was conducted in the context of a children's hospital in Finland and which focuses on the experiences of child patients between 7 and 10 years of age and teens aged 11 to 17 years. In the study, two participatory research methods were applied to investigate the elements of children's PX: photo elicitation and video diaries. The study is part of a larger research project called Lapsus, which has received permission from the ethical committee.

Background

When researching the PX of children, it is important to understand the background of children's cognitive development, how the experiences of children of different ages can be explored as well as the ethical considerations that have to be taken into account when approaching children as research subjects in a hospital.

Children's development and children as research subjects in a hospital
Prevailing theories of cognitive development demonstrate that children understand and perceive the world differently than adults or even children of different ages. As a child grows older, cognitive understanding evolves and eventually the child comes to comprehend the world in a way that is more similar to adults.²¹ Piaget and Inhelder²² divide children's cognitive development into four distinct stages, which every child undergoes in the same order: Sensorimotor stage (0–2 years), pre-operational stage (2–7 years), concrete operational stage (7–11 years) and formal operational stage (older than 11 years). These stages describe the average intellectual development as children's cognitive abilities, such as thinking, reasoning and language skills, evolve and become more sophisticated.

Greene and Hogan²³ have identified three special characteristics with child research: competence, power and vulnerability. Children's cognitive competences, such as thinking, understanding and communication, are still evolving.²³ Children might have limited ability with regard to logical reasoning and abstract thinking.²² Another major distinction, when conducting research with children, is power difference. Children are used to being guided by adults and doing what is expected from them.²³ Thus, they are eager to please and strive to find answers, which they believe to be the right ones.^{24–26} Children are vulnerable, and they might feel that talking with an unfamiliar researcher is intimidating.^{25,27} Thus, relieving tension and

anxiety in the research situation is important.²¹ However, studies have demonstrated that when suitable techniques are used, children are capable of credibly providing information about their own experiences, including aspects related to illnesses and hospitalization.^{12,16,28}

Ethical considerations are in place to ensure the dignity and safety of the child participants.²⁹ The aim of the study and the meaning of the consent have to be explained to the child in an age-appropriate manner. Further, the child needs an opportunity to ask questions of the researcher.³⁰

Participatory research and creative methods

The essence of the participatory approach is the joint process of knowledge production between the researcher and the participant.³¹ It attempts to tap into the participant's direct experiences as they are and give them value.³² In the hospital context, participatory methods are still uncommon and not well accepted,³³ which is due to the ideological clash with participatory and medical paradigms.³⁴ PX is a complex concept and requires a holistic understanding of the patient.^{5,35,36} Thus, commonly used research methods in hospitals, such as surveys, do not fit.^{37,38} Moreover, in order to appropriately facilitate children's participation and study their PX, child-friendly research approaches are needed. Many of the traditional research techniques may not be directly suitable for children.³³ However, researchers see potential in participatory methods and suggest employing them in evaluating hospital care with children.³⁴

Methods

The study applied two methodological approaches to investigate the elements of children's PX: photo elicitation and video diary. The research information was presented both in verbal and written formats to the participating families. Besides the consent from the children's parents, special consent forms were designed for children of different ages (6–10, 11–14 and 15–17 years). It was emphasized that the child had the right to discontinue the study at any time and that participation to the study would not affect the treatment the child received. The data gathered in the study were used only by the researchers and the results were presented anonymously.

Photo elicitation

Photographs are able to provoke responses from research participants and provide a direct look into experiences that might not be easily articulated in other ways.³⁹ The use of photography in research increases children's attention span by capturing their attention for a longer period.⁴⁰ Children enjoy taking pictures and photography does not require any specific abilities.²⁵ It also gives structure for the subsequent interview.⁴¹ Photographs can also reduce possible verbal obstacles, trigger memories and produce unpredictable information.^{40,42} However, the use of

photography also comes with some disadvantages. It may lead participants to focus only on visible phenomena rather than abstract concepts.⁴³ Punch²⁵ also suggests that child participants may take pictures of spontaneous events of modest importance.

The photo elicitation part of this study focused on exploring the patient experiences of children between 7 and 10 years of age during hospitalization and investigating the suitability of the photo elicitation method. The photographs taken by the participants were not intended to stand alone.³³ Instead, the pictures were used as a starting point for a subsequent interview, in which the participants provided a verbal description of the pictures.⁴⁴

The data were gathered in August 2017 in two different units of the children's hospital in Helsinki. These two units focus on providing care for pediatric patients with long-term illnesses: The Day Hospital treats, for example, organ transplantation and cancer patients, and the Rehabilitation Unit treats children with physical or multiple disabilities. In both units, the patients' visits can last for several days, but they do not stay overnight in the hospital.

The pediatric patients were chosen for the study through purposive sampling. The nurse managers of the two units

scrutinized the appointments made for August and listed potential children.

Before arriving at the hospital, potential families were contacted by phone to determine their willingness to participate in the study. The researcher met each of the participants twice: giving introductions soon after they had arrived at the hospital, and interviewing children before they were discharged. The child was asked to take five photographs of items, events or places they liked and, similarly, five photographs of things they disliked in the hospital. Children were provided tablet devices to independently take photographs when they wanted.

Figure 1 illustrates the research setting and shows one participant taking a photograph. The actual photo elicitation interview was organized before the family left the hospital. The child led the discussion and presented the photographs individually to the researcher. As suggested by Mandleco⁴⁵ and Punch,²⁵ two main questions were asked about each picture: What does the photograph represent? Why did the child decide to take that particular photograph? Open-ended follow-up questions were asked about the themes that arose during the conversation.

Figure 1. Participant taking a photograph for the photo elicitation study



One researcher was present at all of the sessions and the children attended together with their parents. A pilot study was conducted with one child before starting the actual research.

Video diary

Cultural probes constitute a research method in which a probe package is intended to evoke responses and feelings in the participant.⁴⁶ One example of a probe is the video diary method, in which the participant produces video clips on given themes. The data gained through video diaries are in-depth,⁴⁷ especially when participants are children.⁴⁸ A video camera can act as a trusted friend⁴⁸ to whom they can talk about feelings and thoughts.⁴⁹ Visual documentaries provide a direct understanding of the participants and their observations and experiences.⁵⁰ Video diaries can provide information that is not possible to obtain through other research methods.^{48,51,52} One reason for this may be that video diaries offer the possibility of investigating both verbal and nonverbal data.⁵³ Video diary clips convey the thoughts, feelings and actions of the participant over a longer period,^{51,52} and these clips can be watched several times.^{53,54}

Video diaries, however, have been criticized as not empowering or spontaneous to all participants, since talking to the video camera may feel uncomfortable⁵⁴ or producing visual data may feel like a burden⁵⁵ to some participants. One limitation of the video diary method is the inability to ask the participant instant follow-up questions.⁵¹ Thus, the reliability of the study depends on how well the researcher can verify the received information.

Figure 2. Contents of the probe package



In this study, the video diary method was applied to explore the patient experiences of children between 10 and 16 years of age. The aim was to learn from the children themselves about the everyday experiences of living with a chronic illness, and to assess the applicability of the video diary method in a health care context.

The data were gathered between January and May 2016 in three outpatient wards of the children's hospital: rheumatism, diabetes and gastrointestinal diseases. The participants received a probe package, which can be seen in Figure 2. The tasks in the binder were modified from McCarthy and Wright's categorization of experience.⁵⁶ For the next nine days, the participants recorded daily video diaries (Figure 3) on the given themes: the composition of illness and the follow-up visits as well as the spatio-temporal, sensual, emotional and social dimensions of illness. Most of the tasks invited children to reveal their feelings toward the illness through drawing, constructing or storytelling. Few of the tasks included direct questions.

Within two weeks of returning the probe packages, the children were interviewed with supplementary questions to clarify possible shortcomings. Before starting the actual study, a pilot study was carried out with one participant to test the intelligibility of the tasks and the time required to finish the probe package

Data and analysis

In the photo elicitation study, the first meetings lasted approximately 10 minutes and the interviews lasted from 10 to 30 minutes. The photo elicitation data contain 64 photographs together with transcripts and recordings of

Figure 3. Participant recording video clips

the interviews. The eight participants were between 7 and 10 years of age and were patients in either the Day Hospital or the Rehabilitation Unit. The time period available to take photographs varied from one to three days, depending on the length of the child's stay at the hospital.

The video diary data, on the other hand, comprised the scanned task sheets, video clips and recorded interviews of the 14 participants, who were between 10 and 16 years of age. The video clips ranged from 3 seconds to 17.5 minutes in length, and were mostly 2 to 5 minutes long. The interviews ranged from 36 to 85 minutes and averaged 55 minutes.

In the analysis of the photo elicitation data, the themes of the photo elicitation interview were used as a basis for grouping the qualitative data. The focus was on the anonymized interview transcripts, in which the children described the photographs they took and gave meaning to their experiences. Positive and negative hospital experiences were analyzed separately. Similar issues from different interviewees were grouped together, resulting in

the following categories: hospital facilities, entertainment, medical care, people and others.

In the analysis of the video diaries, the video clips, scanned task sheets and interview transcripts were utilized. The videos and task sheets were investigated and corresponding notes were made. With the help of ATLAS.ti software and an analysis framework consisting of 16 top-level codings, the qualitative data were analyzed anonymously, resulting in the following themes: hospital facilities, entertainment, everyday life with the illness, meaning of the illness, feelings related to the illness and hospital visits, and future hopes.

Afterwards, the two data sets were analyzed together. The video diary data were richer since they included more tasks and issues including outside the hospital context. In contrast, the photo elicitation study was conducted at the hospital. In order to make the two data sets comparable, only the themes related to the hospital were included in the analysis. Eventually, some of the themes were grouped together resulting in four main categories.

Results

Data and participants

In total, 22 child patients participated in the study (see Table 1). All the participants had been diagnosed with a chronic illness and were recruited through the HUS Children's Hospital.

Children's experiences

Based on the analysis, four main themes of PX of children and teens were identified. These themes and related topics are shown in Table 2 together with the indication of the data source. Each of the four themes is described in more detail in the following subsections.

Hospital facilities and entertainment

Good hospital facilities, especially entertainment, food and pleasurable wards, were respected both by the younger and older children. Toys, fun activities and digital entertainment devices to play games or watch movies were frequently stated as positive experiences. The older children identified puzzles and board games as entertaining. Other fun activities, such as playing the piano or doing arts and crafts, were highlighted in both age groups. Some of the older children were dissatisfied that most of the entertainment was targeted mainly for young children.

A hospital canteen and the opportunity to buy snacks made younger and older children happy. Also, the hospital food aroused positive feelings in younger children (N=3/8). However, the children considered the hospital environment quite negative: patient rooms, hospital beds and lack of privacy were disliked by most. They

Table 1. Demographic characteristics of the participants of the two studies.

Variable		PE	VD	Total N
Gender	Boy	3	3	6
	Girl	5	11	16
Age (years)	7	2	-	2
	8	3	-	3
	9	-	-	0
	10	3	2	5
	11	-	2	1
	12	-	2	2
	13	-	-	0
	14	-	4	4
	15	-	3	3
	16	-	2	2
Diagnosis/ Hospital Unit	Rheumatism	-	6	6
	Gastrointestinal disease	-	3	3
	Diabetes	-	5	5
	Day hospital*	5	-	5
	Rehabilitation unit**	3	-	3

characterized the hospital environment as boring, unsettled and sickly. Nevertheless, the aquarium located in the hospital lobby received acknowledgement by younger children (N=2/8). Watching the view from the window was also perceived as nice. The older children elaborated that they would like the hospital to be more like home: paintings on the walls, plants, mats, pillows and more color (see Figure 4). Also, the older children indicated that they would like to have sofas and beds for parents to stay overnight.

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Medical care

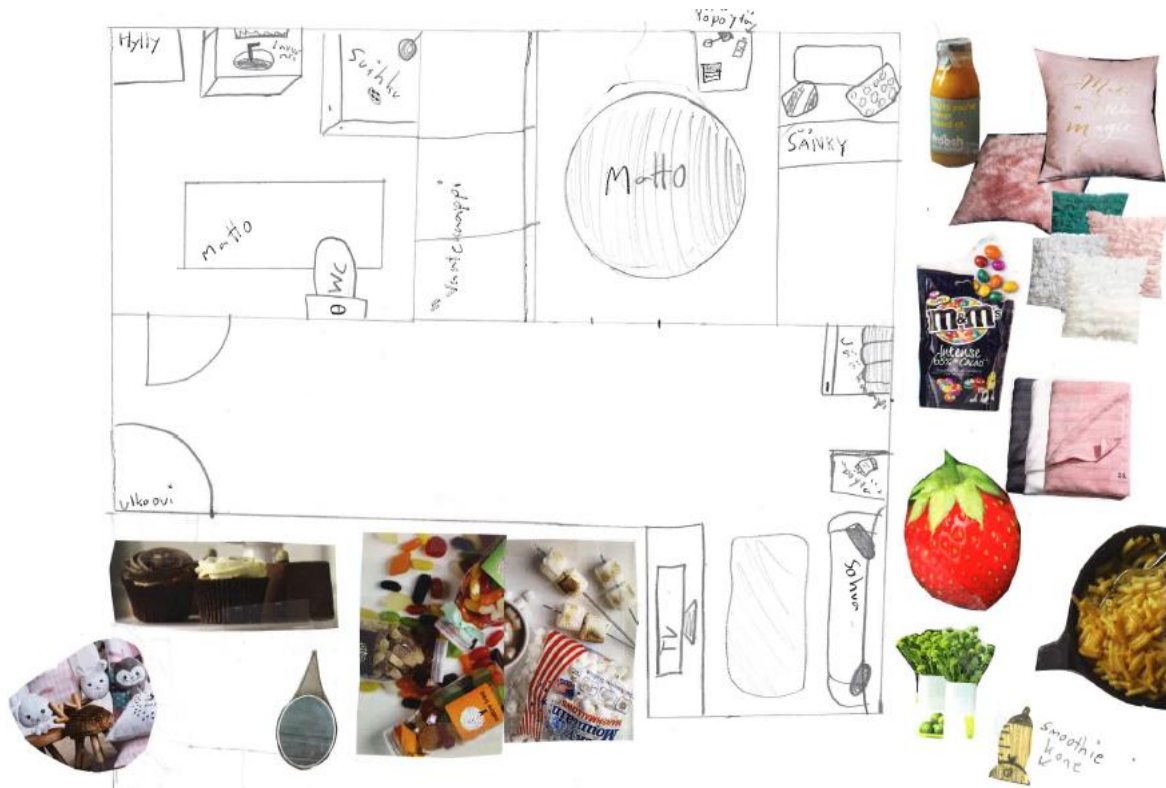
Subjects related to medical care were the most frequently mentioned negative theme around children’s PX. Among the younger children, treatment activities and medical equipment comprised the biggest negative experience category. In particular, invasive activities, such as inserting a cannula and taking samples, were perceived as unpleasant and painful (see Figure 5). Similarly, the older

Table 2. Themes and descriptions of elements of children's PX

Theme	Topic description	Data source		
		+/-	PE*	VD**
Hospital facilities and entertainment	Uncomfortable hospital environment: boring, sickly, lack of privacy	-	5	11
	Digital entertainment, e.g. games, movies	+	3	11
	Hoped to increase the homey atmosphere of the environment			11
	Fun activities, e.g. hospital clowns, arts and crafts, drawing, books, music, puzzles, playing piano or guitar	+	3	9
	Food and snacks	+	5	6
	Toys and playroom	+	4	2
	Nice details in the hospital: aquarium, peaceful areas, views and natural light from the windows	+	3	x
	Hoped for more activities for older children		1	x
Medical care	Invasive procedures	-	6	8
	Hoped to make the hospital visit more convenient: shorter length of the visit, no early mornings, no need to shuttle			6
	Medical equipment, e.g. MRI, ultrasound scanner	-	4	
	Easy, fast and painless activities, e.g. BP measuring, physiotherapy, ECG, pain-relieving patches	+	4	x
	Uncomfortable activities, e.g. dentist's appointment, removing adhesive bandage, taking medicine	-	2	x
Social relationships	Other social contacts important, e.g. parents, friends	+		12
	Long-term relationships with personnel are appreciated	+	2	9
	Hospital personnel are considered positive	+	4	x
	The personnel's way of interacting needs improvement: e.g. busy and uncompassionate personnel disliked	-		3
	Hoped to be met holistically and as individuals			x
Feelings and coping mechanisms	Relief and happiness after hospital visits	+	1	11
	Medical care has become a routine	+		8
	Suspense and discomfort	-	2	8
	Annoyed about constant visits	-		5
	Frightened by new things in the hospital	-		4
	Receiving diagnosis: relief, annoyance or shock	+/-		2,3,2
	Hoped for instant information about condition and treatment			2

*PE = Photo elicitation, the number of participants out of 8 is provided. **VD = Video diary, the number of participants out of 14 is provided. x = applies to this method, + = considered as positive, - = considered as negative.

Figure 4. Dream version of a hospital stay, created by a girl, age 10 (video diary)



[Shows a picture of toy cars] *And this was also nice because I could play with those!* (Boy, age 7)

It would be nice if there was something colorful. I love white, but for a child, I think it is really horrible to spend nights in a totally white room.

I would think "What do I do here?" Therefore, lots of color and paintings on the wall would be nice. (Girl, age 15)

children disliked invasive activities, such as cortisone or insulin injections, that cause pain and bruises and restrict physical activity. Older children (N=8/14) hoped for noninvasive counterparts.

Children identified procedures with medical equipment, such as an infusion pump, MRI or ultrasound scanner, as causing negative experiences, because these devices restrict their normal physical activity. Additionally, the younger children mentioned dentist's appointments and removing an adhesive bandage as negative. Similarly, the older children perceived colonoscopies as nasty and a few participants complained that some medications are unpalatable and cause nausea.

Besides the negative aspects of medical care, younger children (N=4/8) also found some positive issues in the care activities: for example, physiotherapy and blood

pressure measurement were considered as easy, fast and painless in comparison with other medical procedures.

The older children highlighted the impractical nature of the hospital visits and hoped they could be more convenient from the patient's perspective: no early morning appointments, which require them to wake up early, and shorter hospital visits. Additionally, they hoped to reduce the need for the patient to shuttle between different hospital units.

Well, this is when they inserted a cannula in me and I had to wait for a little before they came to do it. It's not really nice when they insert it. [...] Often it is put in already on the first day and then you need to sleep with it. And then it's quite annoying if they, for example, have to take it off and put it in again on the following day. (Girl, age 10)

Taking a blood sample makes me sick, nauseous. They almost never find the vein at once; instead, they have to stick me many times. It does not hurt that much, but I only think about the needle. (Girl, age 14)

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Figure 5. Photograph (considered negative) of an invasive cannula (boy, age 7, photo elicitation)



Figure 6. Photograph of a nice nurse (boy, age 8, photo elicitation)



Social relationships with hospital personnel and other people

Hospital personnel play a major role in the lives of chronically ill children. In the photo elicitation part of the study, younger children (N=4/8) took photographs mostly of their personal nurses, but also of other personnel. Most of these photographs included the participant themselves, either as selfies or as a picture taken by parents (see Figure 6.)

Both the children and the teens appreciated the long-term relationships with the hospital personnel and that they had a personal nurse and doctor. They characterized the personnel as familiar, fun, friendly, fast and nice to talk with. The older participants wanted to be met as individuals and acknowledged holistically. They appreciated if hospital personnel asked them about issues outside illness, for example, about school or hobbies. The children also wanted the information to be explained to them in a positive way. In comparison, the personnel received criticism if they were in a hurry, snapped, focused merely on the illness, did not meet the child empathetically or had the child undress in front of a doctor of the opposite gender. Most of the older participants were satisfied with the personnel, but a few felt the personnel needed to improve their ways of meeting and talking to them.

Some of the teens (N=5/14) mentioned that they liked their parents to be able to stay at the hospital with them. Some teens (4/14) appreciated that the doctors first met only them and afterwards the parents were invited to join.

The older children mentioned their social environment as important: family members, relatives, friends and peers. Family members and close friends helped the participants both in coping with the illness and in practical issues related to the treatments.

This [dentist] was nice! I wrote here "the world's best doctor." She was really fast! She just threw her lamp and caught it and put it there into my mouth. It didn't hurt at all! (Boy, age 8)

I have a personal nurse and doctor. It is nice that they are familiar. It feels maybe easier to talk to them. They know your issues since they have been with you earlier. (Girl, age 14)

Feelings and coping mechanisms of children with illnesses

Visits to the hospital evoked an emotional experience dimension in the children. Suspense was one of the most common feelings the children encountered. Suspense and discomfort were present in the photographs of the younger children portraying situations of waking up from anesthesia, leaving for a medical operation and having to wait (see Figure 7). The older participants felt suspense before the follow-up visits at the hospital, because they were worried if the doctor would have negative news about their condition and illness. Some (N=4/14) older children said that they felt strained in the beginning of the illness and when encountering new types of examinations. In the older children receiving the diagnosis evoked

Figure 7. Negative feeling of leaving for the operation (girl, age 10, photo elicitation).



feelings from relief (N=2/14) to annoyance (N=3/14) and shock (N=2/14).

More than half of the older participants (N=8/14) stated they had learned to live with their illness and that follow-up visits and treatments had already become a routine for them. The study data revealed that participants hoped to receive all the necessary information easily from one place. Some participants claimed that they were not afraid (N=6/14) but enjoyed the visits to the hospital and that their everyday life is enjoyable despite of the illness (N=2/14). In contrast, five of the 14 older participants (N=5/14) were sad and annoyed that they had the follow-up visits so often. Most of the older children expressed that they were relieved and happy when the visit was over, and they got to know the status of the illness and how the treatment continues. One younger child also mentioned that the routine of going to a fast-food restaurant after the hospital visit was rewarding after such a stressful day.

Well, I took this kind of photo. But it's just that I had to wait for so long here. [...] One doctor hadn't come, and we needed to wait for over half an hour.
(Girl, age 10)

When I got the diagnosis, I was okay—now I know what I have and what I need to do. I had never visited a hospital before and now it is a basic thing for me. It was a relief to me to get medication that takes away the pain. (Boy, age 14)

Feedback on the research methods

Photo elicitation method: The participants between 7 and 10 years of age gave mainly positive feedback about the photo elicitation part of the study. For the overall assessment, most of them (N=7/8) reported that it was nice to take part in the study and said that they would like to perform the photography task again if they were given the chance (N=6/8). However, many (N=6/8) perceived it as somewhat difficult to choose what to take photographs of. Most commonly, negative photographs were perceived more difficult to come up with and positive subjects were easier to discover. Children's feedback about the study was brief, and the participants characterized the study mostly with the adjectives "nice" and "fun." One child felt that participating was somewhat stressful and one highlighted that the time period for accomplishing the task was too short.

Video diary method: More than half of the participants (N=8/14) considered that the video diary method was well-suited for investigating the PX of children, and they were pleased with the tasks. Five of the participants mentioned that the method was more fun and probably provided more insights than an interview or survey would have. However, some participants would have preferred a survey or an interview, either face-to-face or via Skype, since interviews were perceived to be easier and faster. Overall, it was appreciated that the tasks and video clips could be conducted in the privacy of the home and the children could spend as much time as needed. Five participants considered the length of the study convenient, whereas three participants would have liked the study to last one or two days less. The use of the method was evaluated more elaborately earlier.¹⁵

Discussion and conclusions

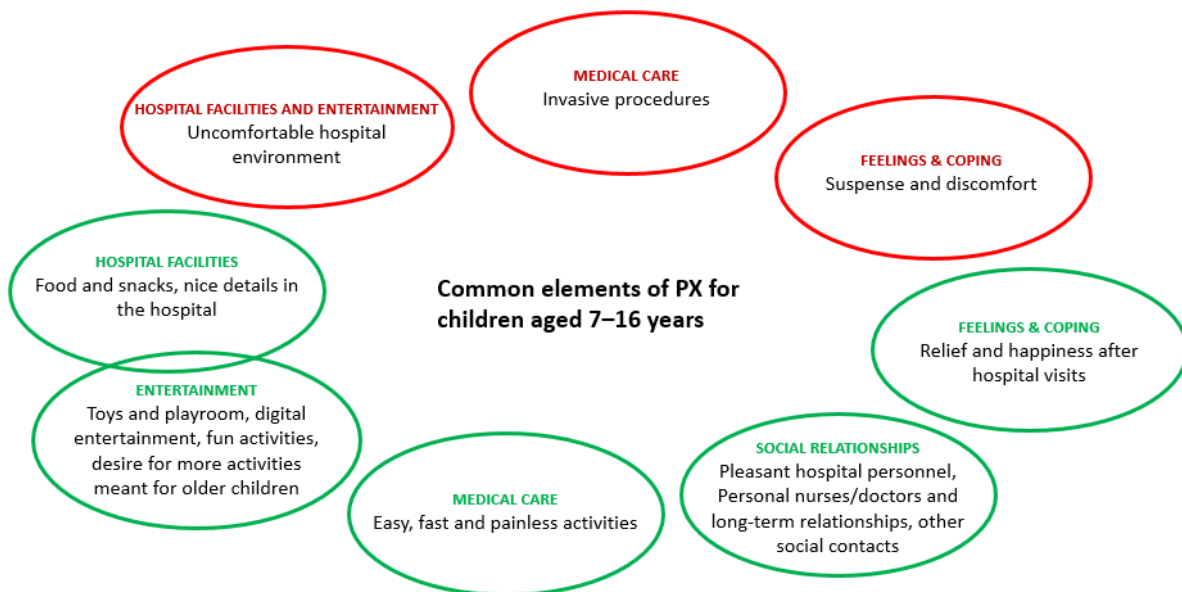
The study identified four main themes of PX of children related to hospitalization: 1) hospital facilities and entertainment, 2) medical care, 3) social relationships with hospital personnel and other people, and 4) the feelings and coping mechanisms of sick children. Each of these themes includes positively and negatively perceived subtopics. Many of the topics presented in Table 2 came from the analysis of both data sets, while some topics occurred only in the photo elicitation or video diary data. Figure 8 presents the common topics for both data sets. Our findings suggest that these form the common

elements of PX for children between 7 and 16 years of age.

Even though many mutual PX topics were found for children of different ages, some variation arose. For example, the video diary data on teens' PX indicated more topics. This is probably due to the fact that teens are more capable of deeper reflections about their experiences, whereas younger children express themselves in a simplified way. The teens also brought up abstract issues and phenomena that were not directly observable in the situation. Social relationships emerged as an important topic, particularly for teens. This was not seen in the photo elicitation results of the younger children, although probably having their parents in the hospital is highly important to them. Possibly, younger children considered the presence of parents as self-evident and were not yet capable of thinking about the possibility of staying in the hospital alone.

Overall, the findings suggest that the hospital experience of children is not invariably negative. The younger participants took more positive photographs; moreover, the majority reported that it was easier to discover positive issues during the hospital visit. Also, the teens were satisfied overall with their hospital visits. They brought up important issues from their everyday lives and, therefore, it seems they define life not through the illness but through everyday events. These findings correspond with previous studies that show that children's positive perceptions in the hospital can outweigh the negative ones.^{3,13}

Figure 8. Common elements of PX for children aged 7–16 years. Negatively perceived issues are circled in red and positively perceived issues are circled in green.



The findings of this study seem to be consistent with earlier research. Issues related to entertainment^{11-13,16,17} and hospital facilities^{11,13,16} have been recognized in other studies. Additionally, hope for a friendly and respectful interaction with hospital personnel has been identified previously.^{11-13,16} Furthermore, the reported findings correspond with earlier observations on the negative nature of invasive devices and procedures,^{11,12,14} the importance of the presence of parents or family,¹¹⁻¹³ the continuity of the health care personnel,^{13,16} contemplating the diagnosis¹² and longing for privacy.¹⁶

It should be noted that the use of different research methods may have influenced the study results: in the photo elicitation method, the children were allowed to take pictures in the hospital of anything they pleased. Alternatively, the video diary method had narrower assignments and the video clips were filmed at home. Due to the varying approaches, the differences between the experiences of younger and older children cannot be directly concluded from the results. Additionally, the sample of the study was quite small, therefore conclusions have to be made cautiously. The relatively high rejection rate (59%) of the video diary study may have also influenced the results of the study: of all the contacted families, 20 declined – 14 of them were boys. Reasons for rejection were lack of time or motivation and personal reasons. In contrast, only one family refused to take part to the photo elicitation part. Still, the rejection rate could not be directly linked to the used method.

The strength of the participatory methods used in this study is that they provide insights on why children and teens appreciate and value some topics or why they dislike and fear other topics. We presented four common elements of PX of children and teens, but equally the methods reveal thoughts and insights outside the mainstream. In this study a teen appreciated the few days spend in hospital because it gave her the chance to rest. Respectively, the study demonstrated that a construction site does not necessarily mean noise and disturbance but can offer amusement, and a seemingly neutral hospital pajama can evoke a gloomy feeling. Hence, we think that photo elicitation and video diaries can be used to gain a deeper understanding about both positive and negative elements related to PX of children and teens – and why not even adults. These methods can be altered to make them easier and more convenient for hospitals to use. Hospitals can ask patients to record video clips and take photographs on a specific theme they want to understand better. By including more interactivity and gamification in the methods, participation might get more interesting.

Still, more research on the topic needs to be undertaken to increase the understanding of the PX of children and what kind of methodological approaches should and could be applied to study the experiences of children of different

ages. Validation and further research on the suggested four main themes of children's PX related to hospitalization is an important issue for future work. Furthermore, this study focused on children between 7 and 16 years of age. A further study with particular focus on children under 7 years of age is therefore suggested.

References

1. Beattie M, Murphy DJ, Atherton I, Lauder W. Instruments to measure patient experience of healthcare quality in hospitals: A systematic review. *Syst rev.* 2015;4(1):97.
2. Coyne I. Children's experiences of hospitalization. *J Child Health Care.* 2006;10(4):326-336.
3. Wilson ME, Megel ME, Enenbach L, Carlson KL. The voices of children: Stories about hospitalization. *J Pediatr Health Care.* 2010;24(2):95-102.
4. Beryl Institute. The Beryl institute creates definition of patient experience. <https://search.proquest.com/docview/751476621>. Updated 2010. Accessed February 28, 2018.
5. Wolf J. Defining patient experience. *PXJ.* 2014;1(1):7-19.
6. Wolf J. The patchwork perspective: A new view for patient experience. *PXJ.* 2017;4(3):1-3.
7. Bishop K. Challenging research: Completing participatory social research with children and adolescents in a hospital setting. *HERD.* 2014;7(2):76-91.
8. Pollari K. Lasten kokemuksia terveydenhuollosta – Euroopan neuvoston lasten terveydenhuoltoon liittyvän kyselyn suomen raportti. *Lapsiasiavaltuutetun toimisto. Hoitotyön koulutusohjelma. Labden ammattikorkeakoulu.* 2011.
9. United Nations. Convention on the rights of the child. Geneva. 1989.
10. EACH The European Association for Children in Hospital. Introduction EACH charter & annotations. <https://www.each-for-sick-children.org/each-charter/introduction-each-charter-annotations.html>. Updated 2016. Accessed February 28, 2018.
11. Coyne I. Children's experiences of hospitalization. *J Child Health Care.* 2006;10(4):326-336.
12. Forsner M, Jansson L, Sorlie V. The experience of being ill as narrated by hospitalized children aged 7-10 years with short-term illness. *J Child Health Care.* 2005;9(2):153-165.
13. Carney T, Murphy S, McClure J, et al. Children's views of hospitalization: An exploratory study of data collection. *J Child Health Care.* 2003;7(1):27-40.
14. Kortessluoma R, Nikkonen M. 'I had this horrible pain': The sources and causes of pain experiences in 4- to 11-year-old hospitalized children. *J Child Health Care.* 2004;8(3):210-231.
15. Karisalmi N, Kaipio J, Lahdenne P. Improving patient experience in a children's hospital: New digital

- services for children and their families. *Approved to be presented in MIE 2018 conference, 24th-26th of April, Gothenburg*. 2018.
16. Curtis K, Liabo K, Roberts H, Barker M. Consulted but not heard: A qualitative study of young people's views of their local health service. *Health Expect*. 2004;7(2):149-156.
 17. Sartain SA, Maxwell MJ, Todd PJ, Haycox AR, Bundred PE. Users' views on hospital and home care for acute illness in childhood. *Health Soc Care Community*. 2001;9(2):108-117.
 18. Burnet D, Gunter KE, Nocon RS, et al. Medical home characteristics and the pediatric patient experience. *Med Care*. 2014;52(11 Suppl 4):S56-63.
 19. New children's hospital. HUS The Hospital District of Helsinki and Uusimaa website. <http://www.hus.fi/en/about-hus/Construction%20projects/New%20Childrens%20Hospital/Pages/default.aspx>. Accessed February 28, 2018.
 20. Uusi lastensairaala 2017. Website available in Finnish and in Swedish. <http://uusilastensairaala2017.fi/>. Accessed February 28, 2018.
 21. Korttesluoma R, Hentinen M, Nikkonen M. Conducting a qualitative child interview: Methodological considerations. *J Adv Nurs*. 2003;42(5):434-441.
 22. Piaget J, Inhelder B, Rutanen M. *Lapsen psykologia*. KJ Gummerus; 1977.
 23. Greene S, Hogan D. *Researching children's experience: Methods and approaches*. Sage Publications; 2005.
 24. Singh I. Capacity and competence in children as research participants. Researchers have been reluctant to include children in health research on the basis of potentially naive assumptions. *EMBO Rep*. 2007;8 Spec No:S35-9.
 25. Punch S. RESEARCH WITH CHILDREN the same or different from research with adults? *Childhood*. 2002;9(3):321-341.
 26. Enright E, O'Sullivan M. 'Producing different knowledge and producing knowledge differently': Rethinking physical education research and practice through participatory visual methods. *Sport, education and society*. 2012;17(1):35-55.
 27. Hill M. Participatory research with children. *Child Fam Soc Work*. 1997;2(3):171-183.
 28. Docherty S, Sandelowski M. Focus on qualitative methods: Interviewing children. *Res Nurs Health*. 1999;22(2):177-185.
 29. Phelan SK, Kinsella EA. Picture this... safety, dignity, and voice—ethical research with children practical considerations for the reflexive researcher. *Qual Inq*. 2013;19(2):81-90.
 30. Lambert V, Glacken M. Engaging with children in research: Theoretical and practical implications of negotiating informed consent/assent. *Nurs Ethics*. 2011;18(6):781-801.
 31. Bergold J, Thomas S. Participatory research methods: A methodological approach in motion. *Historical Social Research/Historische Sozialforschung*. 2012:191-222.
 32. Clark A. Young children as protagonists and the role of participatory, visual methods in engaging multiple perspectives. *Am J Community Psychol*. 2010;46(1-2):115-123.
 33. Carter B, Ford K. Researching children's health experiences: The place for participatory, child-centered, arts-based approaches. *Res Nurs Health*. 2013;36(1):95-107.
 34. Schalkers I, Dedding CW, Bunders JF. '[I would like] a place to be alone, other than the toilet'—Children's perspectives on paediatric hospital care in the netherlands. *Health Expect*. 2015;18(6):2066-2078.
 35. Jorm CM, Dunbar N, Sudano L, Travaglia JF. Should patient safety be more patient centred? *Aust Health Rev*. 2009;33(3):390-399.
 36. Schembri S. Experiencing health care service quality: Through patient's eyes. *Aust Health Rev*. 2015;39(1):109-116.
 37. Carrus B, Cordina J, Gretz J, Nehar K. *Measuring the patient experience: lessons from other industries*. 2016.
 38. Zusman EE. HCAHPS replaces press ganey survey as quality measure for patient hospital experience. *Neurosurgery*. 2012;71(2):N21-N24.
 39. Clark* A. Listening to and involving young children: A review of research and practice. *Early Child Dev Care*. 2005;175(6):489-505.
 40. Dedding, C., Schalkers, I. and Willekens, T. Children's participation in hospital: A short introduction to the theory and practice of involving children in improving the quality of care. *Dutch Child & Hospital Foundation*. 2012.
 41. Fargas-Malet M, McSherry D, Larkin E, Robinson C. Research with children: Methodological issues and innovative techniques. *J Early Child Res*. 2010;8(2):175-192.
 42. Hurworth R. Photo-interviewing. *Qual Res J*. 2004;4(1):73.
 43. Bugos E, Frasso R, FitzGerald E, True G, Adachi-Mejia AM, Cannuscio C. Practical guidance and ethical considerations for studies using photo-elicitation interviews. *Prev Chronic Dis*. 2014;11:E189.
 44. Driessnack M, Furukawa R. Arts-based data collection techniques used in child research. *J Spec Pediatr Nurs*. 2012;17(1):3-9.
 45. Mandelco B. Research with children as participants: Photo elicitation. *J Spec Pediatr Nurs*. 2013;18(1):78-82.
 46. Gaver B, Dunne T, Pacenti E. Design: Cultural probes. *interactions*. 1999;6(1):21-29.
 47. Cashmore A, Green P, Scott J. An ethnographic approach to studying the student experience: The student perspective through free form video diaries. A practice report. *Int J FYHE*. 2010;1(1):106.

48. Noyes* A. Video diary: A method for exploring learning dispositions. *Cambridge journal of education*. 2004;34(2):193-209.
49. Moinian F. THE CONSTRUCTION OF IDENTITY ON THE INTERNET oops! i've left my diary open to the whole world! *Childhood*. 2006;13(1):49-68.
50. Rich M, Lamola S, Gordon J, Chalfen R. Video intervention/prevention assessment: A patient-centered methodology for understanding the adolescent illness experience1. *J Adolesc Health*. 2000;27(3):155-165.
51. Buchwald D, Schantz-Laursen B, Delmar C. Video diary data collection in research with children: An alternative method. *IJQM*. 2009;8(1):12-20.
52. Rich M, Patashnick J. Narrative research with audiovisual data: Video intervention/prevention assessment (VIA) and NVivo. *Int J Soc Res Methodol*. 2002;5(3):245-261.
53. Joseph DH. Videotaped focus groups: Transforming a therapeutic strategy into a research tool. *Nurs Forum*. 2000;35(1):15.
54. Jones RL, Fonseca J, De Martin Silva L, Davies G, Morgan K, Mesquita I. The promise and problems of video diaries: Building on current research. *Qualitative research in sport, exercise and health*. 2015;7(3):395-410.
55. Muir S. Participant produced video: Giving participants camcorders as a social research methods. 2008.
56. McCarthy J, Wright P. Technology as experience. *interactions*. 2004;11(5):42-43