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Pictures of Illness: Photo Elicitation for Studying Patient Experience at Children's Hospital

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Abstract

Healthcare organizations have recently started to collect information about the experiences of their patients. The current feedback methods have been developed mainly for adult participants and the organizations are lacking appropriate instruments for collecting perceptions of children. Also, children's patient experience has yet received little attention in the academic literature.

This thesis focused on exploring how children's patient experience can be studied at the Children's Hospital. The study was conducted as a part of LAPSUS research project. The research questions were the following: (1) Which research approaches and techniques are applicable for studying 6- to 10-year-old children's patient experience? (2) Based on the empirical study, how suitable is the photo elicitation technique for studying children's patient experience?

Four potential research techniques were identified in the literature study and evaluated with medical experts. For the empirical study, photo elicitation technique was chosen and tested in two different units of Children's Hospital in Helsinki. Eight child patients participated in the study. The data consisted of qualitative photo elicitation interviews and 64 photographs portraying children's positive and negative experiences during hospitalization. In the analysis, the data were thematically categorized and additionally, feedback from the participants and hospital personnel were scrutinized.

The results of the study demonstrate the importance of engaging children in studies pertaining to their care. Children have unique experiences which can be utilized in improving the healthcare service. The positive photographs indicated that children value toys and other entertainment, good hospital facilities, friendly nursing staff and painless procedures. Respectively, the negative photographs emphasized the unpleasant nature of invasive operations and the hospital environment.

This thesis provided Children's Hospital a novel way to access patients' perceptions in an age-appropriate manner. The photo elicitation technique will help the hospital identify gaps in the service and improve the child-friendliness of the care. Utilizing photography is applicable and fun both from the perspectives of patients and hospital personnel. Future work is needed to fit the photographing technique to the routines in the hospital and to make necessary adjustments to the instrument.

Keywords Patient experience, photo elicitation, children, hospitalization, children's hospital, research instrument development

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Tiivistelmä

Terveyspalveluita tuottavat organisaatiot ovat alkaneet kerätä tietoa potilaiden kokemuksista palveluidensa parantamiseksi. Nykyiset potilastyytyväisyyskyselyt keskittyvät palautteen keräämiseen aikuisilta, mutta organisaatioilta puuttuvat instrumentit lapsipotilaiden kokemusten selvittämiseen. Lisäksi akateemisesta kirjallisuudesta löytyy vain vähän tietoa lasten potilaskokemuksesta ja sen tutkimisesta.

Tässä diplomityössä selvitettiin miten Lastensairaala voi kerätä tietoa lasten potilaskokemuksesta. Työ toteutettiin osana LAPSUS–tutkimushanketta. Tutkimuskysymykset olivat: (1) Mitkä tutkimusmenetelmät soveltuvat kirjallisuuden mukaan 6–10-vuotiaiden lasten potilaskokemuksen tutkimiseen? (2) Kuinka hyvin valokuvamenetelmä soveltuu empiirisen tiedon perusteella lasten potilaskokemuksen tutkimiseen?

Kirjallisuudesta löydettiin neljä potentiaalista tutkimusmenetelmää, joista asiantuntijahaastatteluiden perusteella valokuvausmenetelmä valittiin empiirisen tutkimuksen kohteeksi. Tutkimukseen osallistui kahdeksan lasta Helsingin Lastensairaalan kahdesta yksiköstä. Aineisto koostui laadullisista valokuvahaastatteluista sekä 64 valokuvasta, jotka kuvasivat lasten positiivisia ja negatiivisia kokemuksia sairaalassa. Tulokset analysoitiin teemoittelua hyödyntäen.

Tutkimuksen tulokset vahvistavat käsitystä lasten osallistamisen merkityksestä. Lapsilla on ainutlaatuisia kokemuksia, joita voidaan hyödyntää organisaation toiminnan kehittämisessä. Lasten positiivisissa kokemuksissa korostuivat lelut ja muut viihdykkeet, tilat ja palvelut, ystävällinen hoitohenkilökunta sekä kivuttomat hoitotoimenpiteet. Vastaavasti negatiivisissa kokemuksissa painottuivat etenkin invasiiviset operaatiot sekä sairaalaympäristön tylsyys.

Valokuvamenetelmä tarjoaa Lastensairaalalle uudenlaisen ja lapsilähtöisen tavan kerätä palautetta potilailta. Menetelmän avulla voidaan tunnistaa palvelun ongelmakohtia ja kehittää sairaalan toimintaa lapsiystävällisemmäksi. Jatkotutkimuksen aiheita ovat valokuvausmenetelmän käyttöönoton suunnittelu sekä tutkimusinstrumentin jatkokehitys.

Avainsanat Potilaskokemus, valokuvamenetelmä, lapset, lastensairaala, sairaalassa olo, tutkimusinstrumentin kehittäminen

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I am extremely thankful for my family and friends for being there for me. Big hugs to my dearest Aapo and Heidi for staying by my side. Thank you for tolerating my endless chatter about the thesis. Thank you also for your unconditioned support even when I decided to cover our house walls with the thesis prints. Thank you also, Mika, for pushing me forward and helping me with the final touches of the thesis.

This is it. Time for a new adventure!

Espoo, November 2017

Hanna Stenhammar

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1 INTRODUCTION

Traditionally, children have been often left out of the scope of studies and researched only through proxies, such as their parents or nurses (see e.g. Stålberg et al., 2016; Pollari, 2011). However, studies have demonstrated that children's experiences do not correspond to those of adults and that children themselves are actually able to provide valuable information about their own perceptions (see e.g. Söderbäck, Coyne and Harder, 2011; Chesney et al., 2005). Consequently, during the past few decades, the focus has been shifting towards recognition of children as active and capable participants in research.

This thesis addresses the problem of how children's patient experience can be studied in pediatric hospital. The study has two objectives. The theoretical objective is to explore and deepen the understanding of studying children and their experiences in a hospital context. The empirical objective is to provide information about the practical use of one selected technique, photo elicitation.

1.1 BACKGROUND AND MOTIVATION

The foundation for child participation arises from the United Nations Convention on the Rights of the Child (1989), which the Finnish government ratified in 1999. Article 12 has the greatest relevance for research purposes since it explicitly obligates for children's participation in an age-appropriate manner:

> *"States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child."* (United Nations, 1989)

Children's rights have a special role in the hospital context. The European Association for Children in Hospital (EACH) has established a Charter with 10 articles to act as a guide for protecting the rights and well-being of sick children. This Charter has been used as a basis for healthcare legislation and guidance in many European countries, including Finland. The Charter includes recognition that children have the right to be informed and to participate in decisions regarding their healthcare (EACH, 2016). Finland is part of an organization of Nordic countries in EACH, called Nordisk förening för sjuka barns behov (NOBAB, in English: Nordic

network for children's rights and needs in health care). This organization promotes the standards in children's healthcare in Finland (NOBAB, 2005).

Hospital context poses challenges for participating and researching patients and in pediatrics, the constraints are substantially increased. Bishop (2014) argues that hospitals hold several organizational, ethical and practical constraints, which form barriers to children's participation and undermine children's interest, ability, and competence to contribute. Organizational culture, skepticism towards qualitative research, access constraints and ethical approvals are among these obstacles. According to Bishop (2014), the demanding nature of the healthcare context is one of the reasons why there is such an incomplete understanding of children's experiences of hospitalization. (Bishop, 2014)

Finnish healthcare organizations possess similar challenges. According to Pollari (2011), customer perspective and healthcare quality have been widely discussed among the Finnish healthcare practitioners, but no concrete actions have been made to systematically gather and utilize patient feedback. Especially, the healthcare experiences and perceptions of children and adolescents have received small attention in research. Pollari (2011) argues that adults might still struggle in recognizing the value of children as informants of their own health. A study conducted with child patients in Finland shows that only 27 % of the respondents said that they have been asked about their experiences of a healthcare visit. These results demonstrate, that there is a need for improvements in order to properly engage children and actively listen to their experiences of care. (Pollari, 2011)

But why is the participation of children so important? For the healthcare organizations to be able to provide services that are responsive to the patient's needs, it is fundamental to engage patients (Beattie et al., 2015). There is no difference in pediatrics, where children's experiential knowledge is required for improving the pediatric hospital services (Coyne, 2006; Carney et al., 2003). Consequently, measuring patient experience, which includes patient's perceptions across the whole patient journey, has become more common in healthcare organizations. Increasingly, studies on patient experience are published but children's perspective has received only a little attention and needs further research (Wilson et al., 2010; Coyne, 2006).

In order to appropriately facilitate children's participation and study their patient experiences, suitable research approaches and techniques are needed. Many of the traditional research methods are primarily designed for adult participants and thus,

they are not directly suitable for children, whose cognitive and linguistic abilities are still limited (Carter and Ford, 2013). Additionally, the paradigm shift from conducting research with children rather than on them necessitates further consideration of methodological issues (O'Kane, 2000). A lack of appropriate techniques for obtaining children's perceptions might even inhibit the participation of children (Singh, 2007; Horstman and Bradding, 2002). Child-centered participatory techniques, which support children's natural way of communication, need to be explored (Carter and Ford, 2013).

This thesis answers to the calls of O'Kane (2000) and Carter and Ford (2013) and studies how children's patient experience can be researched. In the next subchapter, the exact objectives and research questions of the study are presented.

1.2 RESEARCH QUESTIONS AND OBJECTIVES

This thesis addresses the gap in current knowledge on techniques for studying children's patient experience, described in the previous subchapter. The research problem of this thesis is:

How can children's patient experience be studied in the pediatric hospital?

The research problem is first studied through a literature review. The literature study deliberates the theoretical background of children and their experiences as research subjects. It aims to identify the crucial factors affecting the way children's experiences can be successfully accessed. Previous research considering children's experiences in hospital context is carefully examined since the methodological choices in these studies provide an important foundation for addressing the research problem.

The empirical study is used to complement the theoretical understanding with practical evidence. The underlying assumption of this thesis is that by understanding the special considerations of the research subjects, examining the related research and discussing with medical experts, it is eventually possible to select and create a suitable technique for collecting information about children's patient experience. After considering several research techniques, one of them is chosen for the empirical study. Eventually, photo elicitation technique is selected, developed into a research instrument and empirically tested with pediatric patients. The empirical study provides practical information on applying the photographing instrument to the

Finnish pediatric hospital context. The specified theoretical and practical objectives of this thesis are the following:

1. The theoretical objective is to explore and deepen the understanding of issues, which need to be considered when studying children and their experiences in a hospital context. Furthermore, the study evaluates the previous research on children's patient experience and discusses their methodological choices and results.
2. The empirical objective is to provide information about the practical use of the photo elicitation technique in a hospital context. Children's patient experiences are gathered with the technique and the Children's Hospital is given concrete suggestions on how to start collecting data about the perceptions of pediatric patients. A prototype of the research instrument is developed and information on how to refine it is provided.

The research problem is addressed with two main research questions, which are further divided into more specified sub-questions. The first research question is answered through the literature review, while the empirical study provides an answer to the second question.

RQ1: Based on the literature, which research approaches and techniques are applicable for studying 6- to 10-year-old children's patient experience?

- What are the special considerations when studying children and their experiences?
- Which approaches and techniques have been demonstrated successful in researching children's experiences in a hospital context?

In the literature review, constrains and foundations for the research problem are explored. Based on the answers to the first research question (presented in Chapter 2.4), a photo elicitation technique was selected for the empirical study and addressed through the second research question.

RQ2: Based on the empirical study, how suitable is the photo elicitation technique for studying children's patient experience?

- What kind of experiences can the photo elicitation technique unveil from pediatric patients?
- How do children and their parents, hospital personnel, and researcher assess the use of the technique?

This study contributes to multiple fields of research, such as patient experience, service design, child research and participatory approaches. The practical contributions are relevant for pediatric healthcare organizations, which wish to provide better service for their patients.

1.3 CONTEXT AND SCOPE OF THE STUDY

This thesis is written as a part of LAPSUS research project (Finnish project name: Lapsiperheiden uudistuva sairaala, in English: Renewing Hospital for Children and their Families) and contributes by providing information about measuring children's patient experience. The empirical study is conducted at the current Children's Hospital in Meilahti but ultimately, the research instrument is developed for the use of the new Children's Hospital, which is due to put into full operation in summer 2018.

New Children´s Hospital (in Finnish: Uusi Lastensairaala) is a project building a new pediatric hospital at the campus of Meilahti in Helsinki. The project started in 2012 and it aims to replace the outdated facilities of the current Children's Hospital. One of the key attributes driving the functional design of the new hospital is patient experience. (KOY Uusi Lastensairaala, 2014)

LAPSUS research project was organized around the novel concept of patient experience, to support the development of the patient experience practices at hospitals. LAPSUS is a joint project of two universities and three medical organizations: Aalto University, Tampere University of Technology, Hospital District of Helsinki and Uusimaa (HUS), Oulu University Hospital and Turku University Hospital. The project is funded by TEKES.

Patient experience encompasses all phases of the patient journey (Kaipio et al., 2017). This thesis focuses on the hospitalization phase in which a child stays in the hospital for at least one full day. Children included in the study are aged between 6 and 10 years and they have been diagnosed with a chronic illness.

Pediatric healthcare is strongly affected by the fact that the illness of the child influences the whole family and thus, a family-centered approach is recommended (Shields, Pratt and Hunter, 2006). However, this thesis applies patient-centered approach and focuses on the children's perspective. In the earlier phases of LAPSUS research project, parents' perceptions have been widely investigated and hence, there is a need to study the pediatric patients themselves.

Technical implementation of the research instrument is not addressed in this thesis, and neither is a comprehensive plan for putting the instrument into operation. The work focuses on finding and creating a suitable research technique and supporting in developing the first prototype of it.

1.4 RESEARCH APPROACH

This study employs service design approach. It is a holistic and multidisciplinary approach, which combines numerous methods from several disciplines (Stickdorn and Schneider, 2011). Service design can be used to help to innovate new services or improve existing ones (Moritz, 2005). It designs the overall experience of a service, as well as the process and strategy to provide that service (Moritz, 2005). This thesis combines three multifaceted domains: a challenging user group, a demanding context and a novel field of research (see Figure 1). Service design provides assistance when solving complex and even wicked problems (Moritz, 2005), and thus, it is a suitable approach for this study.

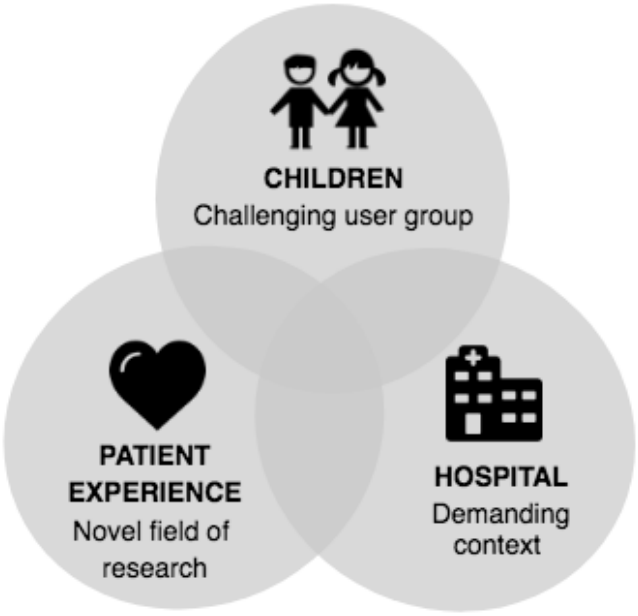

Figure 1: The three domains combined in the thesis

According to Stickdorn and Schneider (2011), service design employs five principles, which are user-centered, co-creative, sequencing, evidencing and holistic. These tenets form also the basis of this thesis: the study is child-centered and holistic in nature, participatory techniques are utilized, and a tangible prototype is developed. Table 1 introduces the principles and the way they are applied.

Table 1: Service design principles applied to this study

Service design principle	Employed in this thesis
1. User-centered	Pediatric patients are put at the center of the study and child-centered approach is applied when creating the research instrument.
2. Co-creative	Various stakeholders are involved. Medical experts are consulted during the development of the research instrument. The research technique applies participatory approach and it is empirically tested with pediatric patients.
3. Sequencing	Patient experience is recognized to encompass all phases of the patient journey. This study focuses on hospitalization phase.
4. Evidencing	A tangible prototype of the research instrument is developed in collaboration with a software company.
5. Holistic	Patient experience is considered in totality and studied with qualitative approach without constricting the dimensions of experience. Pediatric patients are given power and the focus is on their holistic perceptions.

Service design process can be described in many ways but iterative progress and deep understanding of the context and users form the basis of the approach. According to British Design Council (2013), the process is always comprised of three components: researching users and their needs, creating and visualizing solutions, and lastly, prototyping and improving solutions. Design Council (2013) has also created a famous Double Diamond model to visualize the service design process. It divides the process into four distinct phases – Discover, Define, Develop and Deliver (Design Council, 2013). The diamond shape represents how the scope of a study expands and narrows in the course of a project. This Double Diamond model and its relation to this thesis are shown in Figure 2.

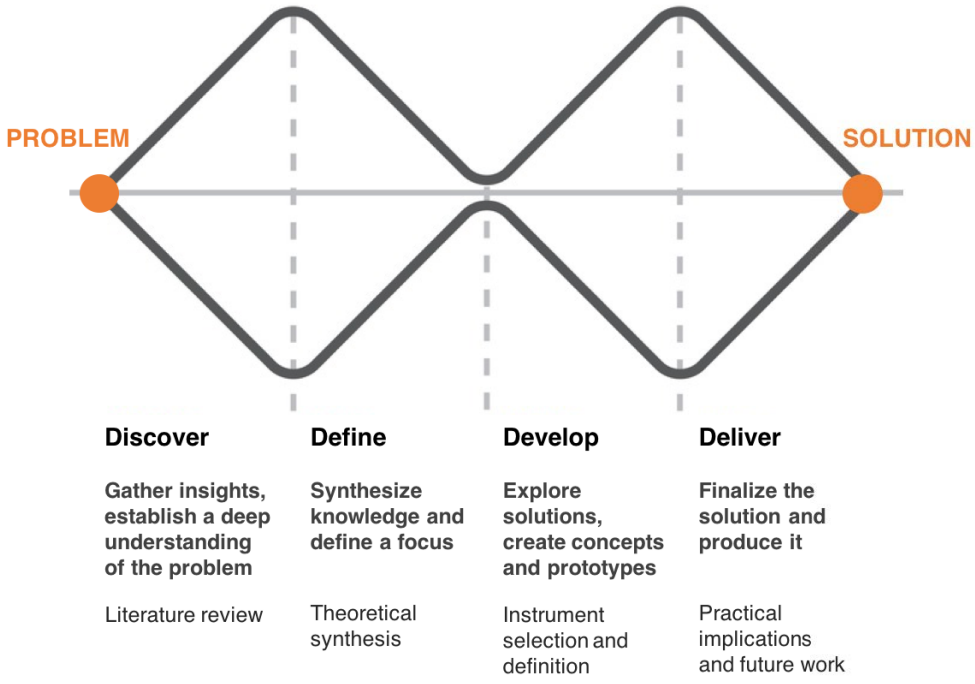

Figure 2: Double Diamond model applied to the study

The service design process of this thesis begins by understanding the problem space by first reviewing the existing literature and then synthesizing the theoretical knowledge and narrowing the focus. After this, the solution space is explored and a prototype of the instrument is created to test it with children. Lastly, the empirical findings are used to draw suggestions on how to refine the prototype for a complete solution. In the scope of this study, it is not possible to do actual iterative development or finalization of the instrument. However, practical implications and future suggestions are provided to guide the revision of the solution.

Besides the service design approach, this thesis applies qualitative approach. Qualitative research explores human-related problems and their meaning to individuals and communities by gaining an in-depth perspective of the topic (Creswell, 2014). Researcher interprets and analyzes the data and hence, it is affected by the researcher's own understanding (Creswell, 2014). Compared to other approaches, qualitative research is holistic and better able to capture the full richness of experience (Greene and Hogan, 2005). Thus, it is well suitable for the context of this thesis. In more detail, the qualitative study in this thesis is phenomenological in nature and concerns the lived experiences of individuals (Creswell, 2014).

2 THEORETICAL BACKGROUND

This chapter consists of a literature review which addresses relevant topics for studying children (2.1) and their experiences (2.2). Related research on children's patient experience is also covered by analyzing the research methods applied and the results gained (2.3). The theories and viewpoints are discussed from 6- to 10-year-old children's perspective and the methodological aspects are highlighted. In the end of the chapter, theoretical synthesis merges the findings from the literature (2.4). It also forms a basis for the development of the research instrument and guides the planning of the empirical study.

2.1 CHILDREN AS RESEARCH SUBJECTS

Children are at the center of this study. As typical for service design projects, it is first essential to gain comprehensive knowledge on the users and gather insights about their special characteristics (Design Council, 2013). In this subchapter, children are first addressed from the perspective of cognitive development (2.1.1), and then from the perspective of research (2.1.2).

2.1.1 CHILDREN'S DEVELOPMENT

Prevailing theories of cognitive development demonstrate that children understand and perceive the world differently than adults or different-aged children. As a child gets older, cognitive understanding evolves and eventually the child comes to comprehend the world in a more similar way with adults. (Kortesluoma, Hentinen and Nikkonen, 2003)

Piaget and Inhelder (1977) divide children's cognitive development into four distinct stages, which every child undergoes in the same order. These stages of development, and an indication of age when an average child undergoes them are the following:

1. Sensorimotor stage (0–2 yrs.)
2. Pre-operational stage (2–7 yrs.)
3. Concrete operational stage (7–11 yrs.) and
4. Formal operational stage (over 11 yrs.) (Piaget and Inhelder, 1977).

These stages describe the average intellectual development from infancy to adolescence. During these steps, children's cognitive abilities, such as thinking, reasoning and language skills evolve and become more sophisticated. During their first years, children are bound to the concrete world and understand it only through

their senses and actions. In pre-operational stage, symbolical thinking and language skills evolve but children perceive the world egocentrically. During the concrete operational stage, children start to understand other people's viewpoints and become capable of logical thinking. Lastly, in the stage of formal operations, the ability to abstract and hypothetical thinking evolves. (Piaget, 1988)

While Piaget emphasizes the phased nature of the development, he also underlines the individuality and continuity of the changes (Piaget, 1988). Although the order of the phases is determined, the age when a child reaches a particular stage varies. Additionally, the transitions between the phases are seamless and no exact changeovers can be distinguished (Piaget and Inhelder, 1977). Therefore, the length of the stages fluctuates and individual differences signify chronological age.

Piaget's theory is one of the well-known models elucidating children's development but it has also received criticism. It has been criticized for its emphasis on age-related competencies rather than on subjective experiences (Greene and Hogan, 2005). Dissatisfaction has also concerned the notion that the theory focuses on the limitations of children's abilities and cognitive skills, rather than on things, which children can already achieve (Rushforth, 1999). Regardless of the limitations of the Piagetian approach, the prevailing opinion is that children's cognitive abilities are still immature and developing (Rushforth, 1999). Also, it can be expected that children within these stages think at least in a manner generally characteristic of the stages (Kortesluoma, Hentinen and Nikkonen, 2003). Next subchapter specifies the characteristics of 6- to 10-year-old children and highlight the special considerations that need to be taken into account when conducting research with children.

2.1.2 SPECIAL CONSIDERATIONS WHEN RESEARCHING CHILDREN

Children are an interesting and challenging user group to conduct research with. Many of the influences affecting studies with adults are respectively relevant with children, but there are some additional factors to be considered (Kortesluoma, Hentinen and Nikkonen, 2003). Greene and Hogan (2005) divide the aspects for differentiating adults and children into three main bases: competence, power and vulnerability. Most of these issues originate from the research setting, in which an adult asks questions from a child participant. Next, these special characteristics are described and their implications for research are discussed.

Competence

The level of children's competencies needs to be taken into account when conducting research with them. Studies have clearly demonstrated differences in children's cognitive abilities, such as thinking, understanding and communication (Greene and Hogan, 2005). The cognitive abilities of children aged between six and ten are characterized by pre-operational and concrete operational stages, which were introduced in the previous subchapter (2.1.1). Depending on the personal differences, children at these ages may show characteristics of one or both of these phases.

Children within this age group can form and understand meanings (Piaget and Inhelder, 1977). They are able to think symbolically and recall subjects that are not currently present and cannot be directly observed (Piaget and Inhelder, 1977). However, children's thinking can be sometimes illogical from the adult's perspective (Kortesluoma, Hentinen and Nikkonen, 2003). In children's world, the reality and imagination coexist and thus, their thinking might be sometimes colored with imaginary things (Forsner, Jansson and Sorlie, 2005). The ability to concrete and logical reasoning start to evolve only at the age of seven or eight (Piaget and Inhelder, 1977). Before this, children act mainly based on their intuition and considerate thinking is still in an insignificant role (Piaget and Inhelder, 1977). The ability to think abstract or hypothetical subjects is still limited and evolves only later when individuals reach the stage of formal operations (Piaget, 1988).

When conducting research with children who have limited ability to understand abstract ideas, it is appropriate to focus on 'here and now' situations. Additionally, the length of the research session should be kept relatively short since small children have a poor attention span. (Kortesluoma, Hentinen and Nikkonen, 2003)

Children differ from adults also in their capabilities in social relationships and communication. Until children reach the stage of concrete operations, their thinking and use of language is egocentric, which leads to difficulties in distinguishing other people's opinions from their own perspective. At the age of seven or eight, the egocentric language disappears and children's social relationships start to become more reciprocal. This allows more complex forms of social behavior to evolve, such as mutual respect and fair collaboration. (Piaget, 1988)

Children might use a different kind of language and have limited vocabulary compared to adults (Punch, 2002). They may show a lack of understanding of

common metaphors and use distinctive expressions (Greene and Hogan, 2005). Thus, the language and questions used during the research should be adapted to children's linguistic skills (Greene and Hogan, 2005; Kortesluoma, Hentinen and Nikkonen, 2003). Because of the differences in language, children's expressions should not be taken for granted (Greene and Hogan, 2005). Punch (2002) remarks that although adults have been children, we see the world from an adult point of view. We should not think that we understand what children mean and make assumptions based on that. Therefore, researchers need to be careful not to impose inappropriate interpretations (Punch, 2002).

To overcome these challenges in communication, Greene and Hogan (2005) suggest that research with children should be a co-constructive process, in which the meaning is mutually negotiated. Children should be given a possibility to explain their answers and be an active participant rather than just a teller (Greene and Hogan, 2005). This is supported by the finding, that open-ended questions increase the reliability of the data gathered from child participants. Open-ended questions invite more accurate and complete answers from children (Lamb et al., 2003). They also allow children to elaborate their answers in more detail, making it easier to notice the inconsistencies between adults' and children's perspectives (Kortesluoma, Hentinen and Nikkonen, 2003). Thus, open-ended questions also reduce the chance for misinterpretation. In contrast, closed-questions convey information from the researcher, limit the child's response options, and foster guessing (Lamb et al., 2003). Especially questions that can be answered only with 'yes' or 'no' answer, should be avoided when studying children (Kortesluoma, Hentinen and Nikkonen, 2003).

Children's limited competences do not need to prevent them from participating in research. Singh (2007) emphasizes that the developmental capacities must be taken into account when planning research with children, but they should not be used as a reason to inhibit children's active participation. Instead, these limitations should be considered as a challenge for researchers to apply and motivate creative and age-appropriate methods (Singh, 2007). Studies have demonstrated that when suitable techniques are used, children are capable of credibly providing information about their own experiences – also related to illnesses and hospitalization (Forsner, Jansson and Sorlie, 2005; Curtis et al., 2004; Docherty and Sandelowski, 1999). According to Docherty and Sandelowski (1999) children even as young as 3 years old, are able to tell their perceptions of hospitalization. Besides being knowledgeable and capable

participants, children are also demonstrated to be willing to take an active role (Stålberg, Sandberg and Söderbäck, 2016; Ben-Arieh, 2005).

Power

Another major distinction, when conducting research with children compared to adults, is power difference. It is closely related to status, size, strength and institutional position, in which adults have authority over children. Children are used to being guided by adults and doing what is expected from them. Furthermore, children might find it difficult to disagree with adults or tell things they assume are unacceptable. (Greene and Hogan, 2005)

Children are eager to please and strive to find answers, which they believe to be the right ones (Singh, 2007). Thus, children might exaggerate or even lie to appeal to the researcher (Punch, 2002). Greene and Hogan (2005) mention that it might be difficult to distinguish the experience that truly happened to a child from an imaginary story, which the child tell only to fascinate the researcher. Children also easily feel that they must try (Punch, 2002). As a result, they might even answer to bizarre and nonsensical questions, especially if the questions are presented in a closed format (Waterman, Blades and Spencer, 2000).

One way to even out the power difference is to let children make some decisions in the research situation (Curtis et al., 2004). For instance, they can be given an opportunity to influence the research instruments or to some extent direct the course of the interview (Ben-Arieh, 2005). It is also important not to pressure children and aim to create the research situation as respectful and non-threatening as possible (Greene and Hogan, 2005). Children need to be assured that there are no right or wrong answers and everything they say is valuable (Kortesluoma, Hentinen and Nikkonen, 2003).

Vulnerability

Young children are more vulnerable and context-dependent than adolescents and adults (Kortesluoma, Hentinen and Nikkonen, 2003). They have physical and cognitive deficiencies, they are open to influence and dependent on other people (Greene and Hogan, 2005). Children get stressed more easily than adults and do not necessarily understand what it means to participate in a research (Kortesluoma and Nikkonen, 2004). In the context of this thesis, children are vulnerable because of

their young age but also because of their illness, possible pain and hospitalization (Kortesluoma, Hentinen and Nikkonen, 2003).

Children might experience talking with unfamiliar researcher intimidating (Hill, 1997). Thus, relieving tension and anxiety in the research situation is important (Kortesluoma, Hentinen and Nikkonen, 2003). Constructing confidential relationship and building rapport alongside with getting to know the child before starting the actual study is recommended (Kortesluoma, Hentinen and Nikkonen, 2003). Building rapport can be accomplished for instance by playing or drawing pictures with the child (Kortesluoma and Nikkonen, 2004).

It should be taken into consideration that the whole research setting is highly sensitive to various interferences (Kortesluoma, Hentinen and Nikkonen, 2003). Children are vulnerable to persuasion and adverse influence (Greene and Hogan, 2005). They are susceptible to external cues and easily influenced by suggestive interview style, for instance (Greene and Hogan, 2005). Therefore, the researcher's skills and the phrasing of the questions play an important role when studying children (Kortesluoma, Hentinen and Nikkonen, 2003).

For children, familiar environments and parental support are important (Gibson et al., 2010). According to Kortesluoma, Hentinen and Nikkonen (2003), these strong social and emotional relationships cannot be ignored by researchers. However, there is no consensus in the literature whether the presence of parents is beneficial in the research setting or not. On one hand, the presence of the attachment figure might be desirable and reassure the child but on the other hand, it may also interfere the conversation and influence the child's answers (Greene and Hogan, 2005).

2.2 RESEARCHING EXPERIENCES

Experiences, especially patient experiences, are of the special interest in this thesis. Since this study addresses the problem of how children's patient experience can be studied in a pediatric hospital, it is essential to understand what experiences really are. Next, experiences are explored from two perspectives: first, they are described from the children's viewpoint (2.2.1) and then, existing literature on patient experience is described (2.2.2).

2.2.1 CHILDREN'S EXPERIENCES

Experiences are embedded part of human living and everything we do and see are related to experiences. In Merriam-Webster dictionary, the term experience is defined as:

> *"Something personally encountered, undergone, or lived through."* (Merriam-Webster, 2017).

Hence, the experience is always personal in nature and concerning a particular person rather than anyone else. Due to this personal nature, experiences are partly inaccessible for an outsider. In fact, even the persons themselves are not aware of all their experiences, because of mechanisms such as denial. People are only able to communicate experiences, which they are conscious of. Additionally, they can only report their experiences in a manner that they have interpreted them. (Greene and Hogan, 2005)

Regarding children, the situation is even more complex. Children are able to consciously process and identify only a small amount of their experiences and they have a limited ability to report these encounters for other people (Greene and Hogan, 2005). Furthermore, when we take into account the cognitive and verbal differences between children and adults, the possibility to access children's experiences in a research setting is quite limited (Greene and Hogan, 2005). Altogether, it is difficult for adults to comprehend children's emotions and experiences, and it is never possible to access them fully (Kortesluoma, Hentinen and Nikkonen, 2003).

In order to gather information about subjective experiences, the individuals themselves have to be consulted. These individuals have the unique knowledge about their own lives, which only them can provide an insight into (Dedding, Schalkers and Willekens, 2012). Accordingly, children are the best-informed people to tell about their daily lives (Greene and Hogan, 2005; Ben-Arieh, 2005). In that respect, they have an expert role to their experiences (Greene and Hogan, 2005).

Qualitative and individual methods are suggested when researching experiences. Qualitative approaches are more open-ended, narrative and holistic and thus more able to capture the full richness of an experience. Additionally, individual and private research settings are generally better for exploring personal experiences, which might include sensitive issues. (Greene and Hogan, 2005)

2.2.2 BACKGROUND TO PATIENT EXPERIENCE

The world is living in an experience economy, where value is created through individualized and compelling service experiences (Pine and Gilmore, 2013). Companies are focusing on customer experience as their strategy to gain a competitive advantage over their rivals (Zomerdijk and Voss, 2011). Like other companies, healthcare organizations have also started to pay attention to patient experience.

There are clear distinctive features between customer experience and patient experience. In the context of healthcare, the service providers offer care for their customers, i.e. patients, who experience this by hospitalization, for instance. However, as Torpie (2014) states *"healthcare is not like other businesses and patients are unlike other kinds of customers"*. She emphasizes that in hospital context the relationship between the clinician and the patient is beyond customer service – it is a therapeutic contact. This special kind of interaction concentrates on giving care to an individual patient, not only providing a service to a customer. In order for this relationship to work, connection, respect and compassion are required. (Torpie, 2014)

Patients also differ from traditional customers in their fundamental situation. Patients acquire services, which generally require an enormous level of trust towards their service provider. Additionally, due to patients' illnesses and health conditions, they might be in a situation in which they need to do important and complex decisions quickly and in a state where they are vulnerable, scared, in pain, medicated, exhausted, or confused. As a consequence of this specific circumstance, patients' expectations and needs are simpler than traditional customers'. (Torpie, 2014)

There is no widely accepted definition of patient experience (Beattie et al., 2015; Wolf et al., 2014). In this thesis, a definition by The Beryl Institute is followed. It explains patient experience as follows:

> *"The sum of all interactions, shaped by an organization's culture, that influence patients' perceptions across the continuum of care."* (The Beryl Institute)

As it can be perceived from this definition, the concept of patient experience is ambiguous, complex, and multidimensional (Beattie et al., 2015; Zusman, 2012). It encompasses all the phases during the patient journey, including diagnostic stage,

hospitalization, recovering at home, visits to the doctor's practice and returning to the everyday life (Kaipio et al., 2017).

Measuring patient experience is fundamental for healthcare organizations to be able to improve their services and their quality (Beattie et al., 2015; Carrus et al., 2015). This applies also for pediatric care, in which children's experiential knowledge helps to provide services that are responsive to child patients' needs (Dedding, Schalkers and Willekens, 2012; Coyne, 2006; Forsner, Jansson and Sorlie, 2005; Carney et al., 2003). Measuring patient experience provides an opportunity to identify and address problems and gaps in the service and monitor the effects of interventions (Beattie et al., 2015). It provides a way to effectively manage the organizational performance and to enhance strategic decision making (LaVela and Gallan, 2014). Additionally, it creates a possibility to compare healthcare providers and benchmark hospital performance (LaVela and Gallan, 2014). In fact, patient satisfaction is becoming an increasingly important advantage in the competition between the healthcare organizations in the United States (Carrus et al., 2015). In 2012 hospital value-based purchasing initiative was launched in U.S. hospitals making the patient experience scores directly affecting the level of healthcare organization's reimbursements (Zusman, 2012).

Patient experience should be studied in a way that produces reliable, valid, and usable data, which can be utilized in practice (Beattie et al., 2015). Additionally, cost-efficiency, acceptability, and educational impact should be taken into account when developing a patient experience instrument (Beattie et al., 2015). It is suggested that patient experience is measured as close to the care encounter as possible (LaVela and Gallan, 2014). According to a research conducted in Norwegian hospitals, the timing of the survey affects the patient-reported experiences and patients report worse experiences when the measurement is conducted a lengthier time from the hospital visit (Bjertnaes, 2012).

Researching children's patient experience helps not only to improve the hospital services in organizational level, but it also makes it possible to adapt to personal preferences. This more individualized approach allows children to express their fears and anxieties and as a result, nurses can respond to those concerns (Coyne, 2006). Researching pediatric patients' experiences helps nurses to understand children's lives in hospital and to support them in unfamiliar procedures (Kortesluoma, Hentinen and Nikkonen, 2003). Furthermore, eliciting and accommodating children's individual preferences supports children's autonomy so that they feel

having control over events in hospital (Coyne, 2006). This, in turn, alleviates children's anxieties and promotes successful outcomes in pediatric care (Coyne, 2006).

2.3 STUDYING CHILDREN'S PATIENT EXPERIENCE

Several papers have recently been published studying children's experiences on healthcare, hospitalization and illness. Children have been researched about their experiences on short-term care (Stålberg, Sandberg and Söderbäck, 2016; Forsner, Jansson and Sorlie, 2005; Sartain et al., 2001), on chronic diseases (Gibson et al., 2010; Noyes, 2000), and on hospitalization (Ekra and Gjengedal, 2012; Pelander and Leino-Kilpi, 2010; Wilson et al., 2010; Coyne, 2006; Lindeke, Nakai and Johnson, 2006; Carney et al., 2003). Their perceptions of hospital fears (Salmela, Aronen and Salanterä, 2011) and pains (Kortesluoma and Nikkonen, 2004) have also been examined. Additionally, studies focusing on hospital environment (Horstman and Bradding, 2002) and children's overall views on healthcare have been conducted (Bokström et al., 2015; Schalkers, Dedding and Bunders, 2015; Pollari, 2011; Chesney et al., 2005; Curtis et al., 2004).

Next, these prior studies are addressed from two perspectives. First, methodological issues are presented and different techniques are evaluated (2.3.1). Second, the results of these studies are introduced, and both positive and negative perceptions of hospitalization and illness are described (2.3.2).

2.3.1 APPROACHES AND TECHNIQUES FOR STUDYING CHILDREN IN HOSPITAL CONTEXT

Several different approaches and techniques have been used to study children's experiences in a hospital context. Many studies have incorporated multiple methods – either different methods for different-aged children or a multi-method approach (see e.g. Stålberg, Sandberg and Söderbäck, 2016; Schalkers, Dedding and Bunders, 2015; Gibson et al., 2010). However, next, these techniques are discussed individually. There are several ways to categorize the techniques and here the following division is used: researching children by proxies, traditional methods, and creative methods.

Researching children by proxies

Patient experience has been little researched through child patients themselves. Instead, parents or nurses have often been used as proxies for children's experiences, while children's own perspective has been ignored (Stålberg, Sandberg and Söderbäck, 2016; Pollari, 2011; Coyne, 2006; Forsner, Jansson and Sorlie, 2005). An example of a method developed for parents of pediatric patients is a Child HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems) survey (Toomey et al., 2015). In this questionnaire, parents are asked to evaluate their child's care by answering to 39 patient experience statements (Toomey et al., 2015).

However, studies have demonstrated that other people, such as parents or nurses, do not really comprehend how children think, feel or experience things (Söderbäck, Coyne and Harder, 2011). They perceive healthcare services differently than children (Bone et al., 2014). For example, a study researching children's pain experiences showed that neither the parents' nor the nurses' assessment of the child's pain level corresponded to the actual pain reported by children themselves (Kortesluoma and Nikkonen, 2004). Similarly, in a comparative study by Chesney et al. (2005), children and their parents rated and evaluated the received pediatric care differently. These results raise a question whether it is appropriate to ask only parents to evaluate the healthcare on behalf of their children. According to Lindeke, Nakai and Johnson (2006), if only parents are queried, important and insightful perspectives of children are missed that could lead to improvements in care quality.

Traditional methods

Researchers have applied a variety of traditional techniques for gathering information directly from children themselves. Questionnaires and interviews have been used to study children's experiences in a hospital context.

Chesney et al. (2005) conducted a questionnaire study, which aimed to compare child patients' and their parents' satisfaction ratings of pediatric care. Even children as young as four years old were able to participate, as nurses assisted them by reading the survey and recording their answers. The researchers reported that the study was successful and that the survey was easy to administer and yielded interesting results (Chesney et al., 2005). Additionally, Ombudsman in Finland conducted a questionnaire study to investigate the perceptions of children and adolescents about healthcare in Finland (Pollari, 2011). Pollari (2011) was surprised that although the survey was relatively long, many children under 10 years old were

willing to participate. However, she states that the survey was clearly targeted to older children, which possess a severe problem for younger participants (Pollari, 2011).

In some studies, qualitative interviews were employed as the main source of information. Coyne (2006) conducted semi-structured in-depth interviews with children aged 7–14 years with chronic illness about their fears and concerns in hospital. Respectively, Kortesluoma and Nikkonen (2004) interviewed 4- to 11-year-old children about their pain experiences. In these studies, interviewing method was regarded as a suitable choice to support children with sharing their hospital experiences. Interviews have also been used as a supportive data gathering technique in several studies (see e.g. Schalkers, Dedding and Bunders, 2015; Gibson et al., 2010; Noyes, 2000).

Traditional methods have been historically developed for adult participants (Carter and Ford, 2013). They might require skills, which children do not yet possess and thus, more child-centered techniques are recommended to be given a priority (Ellingsen, Thorsen and Størksen, 2014). Additionally, patient experience surveys have received much critique (Wolf et al., 2014). It has been questioned whether quantitative questionnaires can access all the aspects of patient experience and measure it accurately (Carrus et al., 2015; Zusman, 2012). Thus, moving beyond questionnaires is suggested (Wolf et al., 2014).

Creative methods

Variety of different creative methods have been applied for studying children's experiences in a hospital environment. Creative methods have been characterized suitable for research with children (Carter and Ford, 2013). They allow researchers to access the world of children through things that children are familiar with: stories, drawings and puppets (Greig, Taylor and MacKay, 2007). As Driessnack (2005) describes, they can act as 'doorways' inviting to the children's world. According to Greene and Hogan (2005), creative methods can serve as *"constructivist tools to assist research participants to describe and analyze their experiences and give meaning to them"*. When using creative methods, either ready-made stimulus materials or artwork created by the children themselves can be applied.

Visual stimulus materials, such as pictures or feeling cards, have been used in research to help children recall events and express their views (Bone et al., 2014; Salmela, Aronen and Salanterä, 2011; Curtis et al., 2004; Carney et al., 2003). For

example, Salmela, Aronen and Salanterä (2011) utilized ready-made pictures portraying a fairy figure in a hospital environment to encourage children to express their hospital fears. Written prompts, such as sentence completion, have also been used to research children's perceptions (Pelander and Leino-Kilpi, 2010).

Art-based approaches, such as narratives, roleplays and visual arts, have resonance with children's everyday lives (Carter and Ford, 2013). Through artwork, children can accurately and vividly convey their perceptions. Storytelling is a natural way for children to communicate, and thus, narratives (Wilson et al., 2010; Forsner, Jansson and Sorlie, 2005), play (Gibson et al., 2010; Aldiss et al., 2009; Curtis et al., 2004) and written stories (Schalkers, Dedding and Bunders, 2015) have been also exploited in the hospital context. For instance, Wilson et al. (2010) studied the hospital experiences of 5- to 9-year-old children by inviting the children to tell stories about particular aspects of hospitalization.

The most common individual art-based technique to access children's world is drawing (Driessnack and Furukawa, 2012). Drawings have been utilized in several studies researching children's hospitalization or pain experiences (Stålberg, Sandberg and Söderbäck, 2016; Gibson et al., 2010; Curtis et al., 2004; Carney et al., 2003; Horstman and Bradding, 2002; Sartain et al., 2001; Noyes, 2000). For instance, in a study conducted by Sartain et al. (2001) children's drawings portraying stay in home and in hospital were used as a basis for an interview.

Photographing is another creative way to access children's perceptions. Schalkers, Dedding and Bunders (2015) studied children aged between 6 and 18 years about their perspectives on a pediatric hospital in Netherlands incorporating multiple research methods, including photographs. Pediatric patients were asked to take photographs of things and places they liked and did not like in hospital. As a result, the photographs helped to understand children and produce concrete points for improvements, to which the hospital managers could respond (Schalkers, Dedding and Bunders, 2015). Additionally, photographs have been used in Norway to study the experiences of 6- to 12-year-old child patients with diabetes (Ekra and Gjengedal, 2012). In this study, the use of photographs made it easier for children to describe their experiences of hospitalization (Ekra and Gjengedal, 2012).

Creative techniques have multiple benefits. They are an indirect and non-threatening way to allow children to express perceptions, which they might not even be consciously aware of or able to express verbally (Bellack and Fleming, 1996).

Creative methods enable children to feel more comfortable in the research setting (Punch, 2002). Additionally, these methods can be more interesting and fun, which is an important quality when studying children (Punch, 2002). However, the use of creative methods is not always scrutinized and thus, there is a concern about the usefulness and reliability of the data these methods provide (Punch, 2002). Additionally, there is a concern regarding the analysis of results. Special caution needs to be addressed in order not to impose adult assumptions and misinterpret children's artwork (Punch, 2002).

2.3.2 CHILDREN'S PERCEPTIONS OF HOSPITALIZATION

According to the prior studies, children's overall views of hospitalization are not invariably negative but the positive perceptions can even outweigh the negative ones (Wilson et al., 2010; Carney et al., 2003). Next, both positive and negative aspects of children's perceptions of hospitalization are presented. Only findings from studies, which gathered data directly from children themselves are incorporated.

Children perceive social relationships important during their healthcare visits. Being alone in the hospital make children feel scared and insecure and they want protection and comfort (Wilson et al., 2010). The presence of family members, especially parents, is essential for hospitalized children (Stålberg, Sandberg and Söderbäck, 2016; Forsner, Jansson and Sorlie, 2005; Sartain et al., 2001). Also, social relationships, both with the hospital personnel and with other child patients, are perceived as redeeming features of hospitalization (Pelander and Leino-Kilpi, 2010; Lindeke, Nakai and Johnson, 2006; Curtis et al., 2004; Sartain et al., 2001). Children consider it significant that the nurses are sensitive and respectful (Curtis et al., 2004; Sartain et al., 2001). They wish to be heard by the hospital personnel and receive information about their care (Stålberg, Sandberg and Söderbäck, 2016; Bone et al., 2014; Curtis et al., 2004; Horstman and Bradding, 2002; Sartain et al., 2001; Alderson and Montgomery, 1996). Additionally, the continuity between the hospital personnel is valued (Curtis et al., 2004).

Children also highlight the importance of the hospital environment. They dislike the aspects, which make hospital feel different than home, e.g. distinctive bed, lack of privacy or noisy environment (Gibson et al., 2010). They report to value good facilities, especially well-equipped playroom with toys (Bone et al., 2014; Aldiss et al., 2009; Curtis et al., 2004; Sartain et al., 2001) or entertainment devices (Gibson et

al., 2010). Children mention fun activities and playing as the best things in the hospital (Pelander and Leino-Kilpi, 2010; Lindeke, Nakai and Johnson, 2006).

Several studies have shown, that hospitalization is a stressful event for children and causes anxiety, fears, and concerns (Coyne, 2006; Forsner, Jansson and Sorlie, 2005). Pain and discomfort together with physical treatments and symptoms of illness are among the essential concerns children have in a hospital (Salmela, Aronen and Salanterä, 2011; Pelander and Leino-Kilpi, 2010; Lindeke, Nakai and Johnson, 2006). Separation from family and being left alone in an unfamiliar environment causes anxiety (Salmela, Aronen and Salanterä, 2011; Coyne, 2006). Children also report to miss their friends and sporting activities (Coyne, 2006). Fear of the unknown illustrates many children's feelings (Bone et al., 2014; Horstman and Bradding, 2002). Hospitalization causes disruption to children's normal everyday life, family routines and school attendance (Pelander and Leino-Kilpi, 2010; Coyne, 2006). The loss of independence and self-determination creates negative feelings (Coyne, 2006). The stay in a hospital includes boredom and long waiting times (Bone et al., 2014; Pelander and Leino-Kilpi, 2010; Curtis et al., 2004; Sartain et al., 2001). Also, the lack of information together with several instruments and equipment cause fears in some children (Salmela, Aronen and Salanterä, 2011; Horstman and Bradding, 2002). Lastly, hospital food has introduced a lot of poor feedback from hospitalized children (Coyne, 2006; Curtis et al., 2004).

2.4 THEORETICAL SYNTHESIS

This subchapter synthesizes the literature study and defines the focus for the empirical work. The research problem of this thesis is to study how children's patient experience can be studied in the pediatric hospital. The literature study answers the first research question of which research approaches and techniques are applicable for studying 6- to 10-year-old children's patient experience. This question includes two sub-questions: *What are the special considerations when studying children and their experiences? Which approaches and techniques have been demonstrated successful in researching children's experiences in a hospital context?* Answers to these sub-questions are presented next.

Table 2 provides an answer to the first sub-question and summarizes the major considerations regarding studying children and their experiences. In the table, first, the characteristics of children and experiences are listed. Second, the way these factors affect research is addressed. The literature reviewed in Chapter 2.1 and

Chapter 2.2 suggests that when studying children's experiences, the approach should be co-constructive, qualitative and individual. Age-appropriate techniques, which give power to the child and produce usable data about patient experience are recommended.

Table 2. Summary of considerations when studying children's experiences

	Children (Chapter 2.1)	**Experiences (Chapter 2.2)**
Characteristics	- Limited competences - Power difference between children and adults - Vulnerability	- Personal in nature - Always partly inaccessible - Patient experience is complex and multidimensional
Implications for research	- Use age-appropriate techniques - Apply co-constructive approach - Focus on 'here and now' issues - Give power to the child - Build confidential and non-threatening research setting	- Consult individuals themselves - Favor qualitative and individual techniques - Study patient experience close to the care encounter - Strive to gather data which can be utilized in practice - Take into account cost-efficiency and validity of the instrument

Chapter 2.3 reviewed the related research on children's experiences in the hospital context and provides an answer to the second sub-question. The approaches that have been demonstrated successful in previous studies on children's patient experience were divided into the following three main categories: (1) researching children by proxies; using children as informants and studying them with (2) traditional methods, or (3) creative methods.

The methodological choices of these studies provide background and preconditions to support the selection of the research technique for the empirical study of this thesis. Next, the number of alternative techniques are limited into four. This selection process is roughly illustrated in Figure 3 and described next.

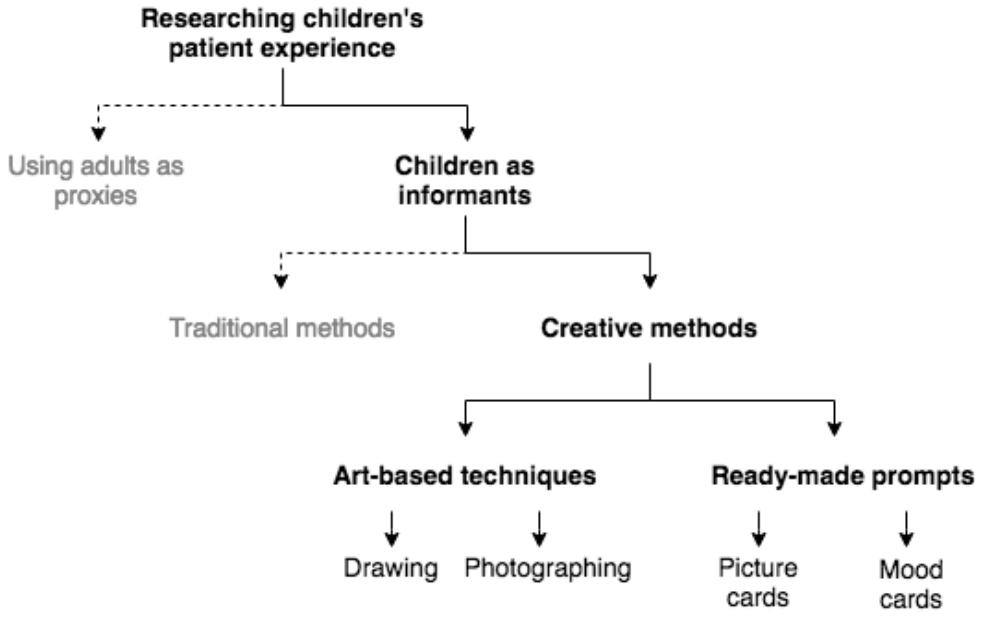

Figure 3. The process of selecting the research technique

Firstly, the related research demonstrates that there are many advantages of researching children directly and using them as informants. The theoretical background regarding children's competencies and the personal nature of experiences also support this. Additionally, UN Convention on the Rights of the Child (1989) endorses children's direct engagement. Thus, the approach of using children as informants is selected as a foundation for this study. Secondly, children themselves can be researched with traditional or creative methods. Creative methods are demonstrated more suitable for children than traditional ones (Carter and Ford, 2013), and hence they are prioritized in this thesis. Creative methods can be further divided into art-based techniques and ready-made prompts, which both have been proved suitable for researching children's experiences.

When selecting the particular creative techniques to be further evaluated, the suitability for the hospital context has to be assessed. Techniques, which for example require spending an extensive amount of time with the child, have to be excluded due to resource restrictions at hospital. Also, techniques relying on textual communication are discarded because of the possible limitations in reading and writing skills of the child participants. Eventually, two artistic techniques, drawing and photographing, and two techniques utilizing visual prompts, picture cards and mood cards, are chosen.

To conclude, four research techniques were selected as solution candidates for the empirical research. In the next chapter, the instrument development is described: the

four techniques are further analyzed, one of them is selected, and an instrument is created. After that, the second research question of this thesis is answered with the empirical study. It addresses the suitability of the selected technique for measuring children's patient experience.

3 INSTRUMENT SELECTION AND DEFINITION

This chapter describes the process of selecting the research technique and developing the instrument prototype for collecting information about children's patient experience. The viewpoints from the theoretical background are exploited to guide the design of the instrument. Next, different solution candidates are explored and the process for selecting the final technique is presented (3.1). Then, the selected technique is described in more detail (3.2), lastly, and the instrument prototype is introduced (3.3).

3.1 SELECTION OF THE RESEARCH TECHNIQUE

Based on the literature study, four creative research techniques were selected as candidates for the empirical part of this thesis (see Chapter 2.4). Two of the alternatives, drawing and photographing, are creative techniques in which children first portray their experiences using artistic means and then the work is exploited in an interview. Another two techniques, picture cards and mood cards, utilize visual prompts to guide the interview session. Brief descriptions of the four research techniques are presented next. After this, it is described how the medical experts were interviewed to evaluate the solution candidates. Based on their perspectives, one of the techniques is selected for further development.

Alternative 1: Drawing

In the first research technique, a child is given a task to draw a picture, which portrays their experiences as a patient in a hospital. The task can be unstructured (e.g. 'My day in the hospital') or more controlled (e.g. 'The best or worst thing in the hospital'). After the drawing is ready, the researcher and the child discuss it: What does the drawing represent? Why did the child decide to draw those particular things? (Punch, 2002) More detailed questions are asked about the themes that arise as the child explains the artwork. Drawings have been exploited in several previous studies. Sartain et al. (2001) and Carney et al. (2003) requested children to simply draw a picture about being in a hospital. Horstman and Bradding (2002) and Gibson et al. (2010) told children to imagine a child like them in a similar situation in a hospital, and draw a picture of them. Lastly, Horstman and Bradding (2002) also experimented with a task suggesting children draw what their ideal hospital looks like.

Alternative 2: Photographing

In this technique, a child is given photographing equipment for a specific time period. They are assigned a task to take photographs, which portray their hospital and patient experiences. As with the drawing technique, the task can be either unstructured or structured. Afterwards, the researcher and the child goes through the pictures and individually discuss each of them: What does the photograph represent? Why did the child decide to take that particular photograph? (Mandleco, 2013; Punch, 2002) More detailed questions are asked about the themes that arise during the conversation (Mandleco, 2013). In previous studies, Schalkers, Dedding and Bunders (2015) asked children to take altogether 10–15 photographs of things and places in the hospital they liked and did not like. Similarly, Ekra and Gjengedal (2012) invited children to photograph things, places and activities they perceived important at the hospital.

Alternative 3: Picture cards

In this alternative, different hospital related situations and issues are discussed with the help of pictorial cards. Picture cards are utilized as visual prompts to provide structure for the conversation and to help a child in recalling occasions (Docherty and Sandelowski, 1999). The picture cards can, for example, include images of nurses and doctors, different treatments or hospital environment. One picture is shown to the child at a time and questions are asked to initiate discussion about the themes of the image. In previous studies, Salmela, Aronen and Salanterä (2011) showed children pictures featuring a fairy character in a hospital environment, and Stålberg, Sandberg and Söderbäck (2016) used pictures representing various healthcare situations.

Alternative 4: Mood cards

This technique utilizes particular mood cards in order to get information about a child's prevailing emotional state. Especially when sensitive topics are touched, feeling cards are useful (Hill, 1997). The cards can, for example, portray a specific character with different emotional expressions. The child selects a card that corresponds the best with their current mood, and afterward, the child's feelings and their possible reasons are discussed. For example, Bone et al. (2014) utilized emotion cards when studying children's perceptions and fears related to mental health services in England.

As learned from the literature study, each of these four techniques is suitable for collecting children's experiences. However, they differ in their basic nature, the equipment they require and the type of data they provide as an outcome. A short summary of the alternative techniques is provided in Table 3. Also, references to the previous studies applying the particular technique with pediatric patients are included in the table.

Table 3: Summary of the alternative techniques

	Art-based techniques		**Ready-made prompts**	
	1. Drawing	**2. Photographing**	**3. Picture Cards**	**4. Mood cards**
Description	Child draws a picture of the hospital experience and afterward, it is discussed	Child takes photographs in the hospital, and they are used as a basis for discussion	Child is shown a visual card and the themes in the picture are discussed	Child chooses a card representing their current mood and the choice is discussed
Equipment	Pens and paper	Camera or a device with photographing functionality	Picture cards portraying things, events and places in hospital	Visual cards representing different emotions
Outcome	Drawing & verbal description	Photographs taken from the hospital & verbal description	Discussion about the theme in the picture	Discussion about child's current mood
Related studies	Sartain et al. (2001)* Carney et al. (2003) Curtis et al. (2004) Gibson et al. (2010) Horstman and Bradding (2002)	Ekra and Gjengedal (2012)* Schalkers, Dedding and Bunders (2015)	Salmela, Aronen and Salanterä (2011)* Curtis et al. (2004) Stålberg, Sandberg and Söderbäck (2016)	Bone et al. (2014) For examples of mood cards, see e.g. Pesäpuu (2017)

** Applied as the main data gathering technique in the study*

Since the aim of the thesis is to develop a research instrument for collecting children's experiential knowledge at Children's Hospital, the context needs to be carefully taken into account when selecting the research technique. The feasibility of

the technique and its fit to the existing practices and resource constraints of the hospital needed to be assessed to ensure the practical impact of the study.

In order to identify the requirements, constraints, needs, and wishes from the perspective of the hospital, HUS employees were consulted. By discussing with the medical professionals, who work with pediatric patients and have knowledge about the new Children's Hospital, the aim was to develop an instrument with maximum value for the hospital. The aim of the interviews was to gather feedback and input that could be utilized when choosing the final research technique and start planning the instrument in more detail. The meetings were organized during May and June 2017. Altogether, four HUS employees were individually interviewed: child psychiatrist, kindergarten teacher, forensic psychologist, and a person working with the new Children's Hospital project. The interviews were informal and unstructured discussions and they lasted from 60 to 90 minutes. The meetings were arranged at the interviewees' offices in Helsinki. Figure 4 below illustrates the whole process of designing the research instrument and the role of the individual interviews during the course of it.

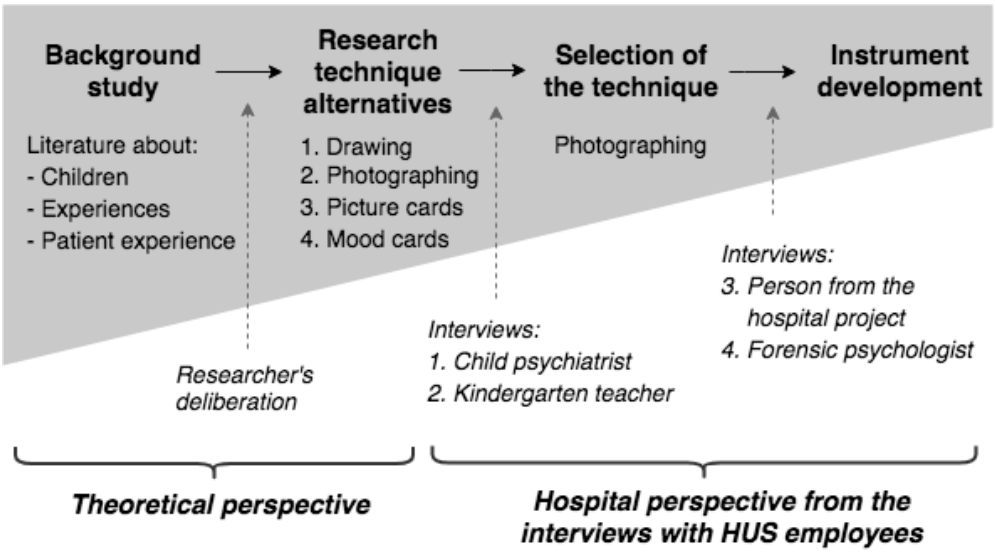

Figure 4: The process of designing the research instrument

As perceived in Figure 4, the first two interviews with the child psychiatrist and the kindergarten teacher were focusing on assessing the different alternative techniques. The interviewees were introduced with the techniques and afterward, they were asked to express their opinions about them. Moreover, the discussions aimed to gather a concise introduction to the practices of how children's experiences are currently researched at HUS.

The meeting with the person from the new Children's Hospital project aimed to give additional consolidation for the selection of the research technique. Furthermore, it was discussed how the technique should be developed into a specific research instrument so that it can provide the greatest value. The last meeting with the forensic psychologist focused on the actual details of the instrument and the research setting. For instance, issues about question formulation and how to research children without leading them were discussed.

As a result of these discussions, photographing technique was selected to be developed further to a research instrument. This technique was preferred by both of the first interviewees and supported in two of the latter discussions. Justifications for the selection is presented next.

The interviewees considered drawing and photographing techniques as alternative solutions that provide relatively similar information about children's experiences. However, photographing was considered more straightforward for the children since the skill level does not play such a big role. Additionally, the interviewees highlighted that with the same effort and time, it is possible to attain a bigger quantity of photographs than drawings, and thus develop a broader overview of the patient experience. However, drawing as a technique was considered easy to administer since only pen and paper are required. The interpretation of the drawings was yet considered as a big risk, which could affect the validity of the results.

Mood cards arouse positive feelings in the interviewees and they were seen as a useful technique. In fact, it was found out that mood cards are currently being used to occasionally research children in some units at HUS. Mood cards were perceived able to capture the essence of the children's 'here and now' characteristics, which is greatly affected by the prevailing emotions. One interviewee remarked, that mood cards could be easily and fast used after every encounter between the hospital personnel and pediatric patients. However, one concern was that young children are still learning to name and identify their emotions, and it might be difficult for them to define what they are currently feeling. It was also questioned whether mood cards can provide information about the multidimensional patient experience without constricting it too much.

The interviewees liked the solution candidate of picture cards the least. It was agreed that using ready-made pictures instead of children's own creations, possesses a great risk of leading children too much. It was mentioned that it is difficult to make such

pictures, which are realistic and portray real situations in the hospital but are simultaneously neutral and not emotionally charged. Small inaccurate details can easily draw children's attention and affect the usefulness of the whole technique.

In summary, photographing technique was considered to provide the most valuable and deepest experience data from pediatric patients with a moderate level of effort from the hospital personnel. Table 4 summarizes the assessment of the alternative techniques given by two experts, the child psychiatrist, and the kindergarten teacher. In next subchapter, using photography in research is discussed in more detail.

Table 4: Assessment of the alternative techniques

	Art-based techniques		**Ready-made prompts**	
	1. Drawing	**2. Photographing**	**3. Picture cards**	**4. Mood cards**
Benefits	- Easy to administer - Allows children to convey emotions	- Easy and effortless for children - Photographing is fun - Allows a bigger quantity of data - Emphasizes child's role as an expert	- Helps in memorizing occasions	- Support 'here and now' nature of children - Fast and easy to administer - Are already utilized in some units at HUS
Drawbacks	- All children do not enjoy drawing - Drawing skills affect the outcome - Interpreting drawings might be difficult	- Privacy concerns: other patients cannot be in the photographs - Describing the photograph can be challenging	- Difficult to create realistic and neutral pictures - Pictures can be leading - Children might find it difficult to relate to the picture - Might compel children to tell imaginary stories	- Young children cannot yet name or identify emotions - Selection of the cards have an effect - Single study might be uninformative without knowing the baseline

3.2 PHOTOGRAPHY IN RESEARCH

The terms for different research techniques using photography are often used in a fuzzy manner (Carter and Ford, 2013). Photo elicitation refers to a more general approach, in which photographs are used to provoke responses from research participants (Hurworth, 2003). Auto-driven photo elicitation highlights that the photographs are taken by the participants themselves, and the participants are leading the discussion about the pictures (Hurworth, 2003). Furthermore, photovoice is a photographing technique strongly linked to a community-based change (Hurworth, 2003). For the purpose of this thesis, photo elicitation is used to refer to an activity in which pediatric patients are instructed to take photographs during their hospital stay and these are used as a basis for an interview about their patient experience.

Photo elicitation belongs to the participatory approach, which signifies the active involvement of participants in the study (Bishop, 2014). The participants are acknowledged as experts and empowered to have their voices heard (Aldiss et al., 2009). The essence of the participatory approach is the non-hierarchical relationship and the joint process of knowledge production between the researcher and the participant (Bergold and Thomas, 2012). It attempts to tap into participant's direct experiences as they are, and give them status and value (Clark, 2010).

Utilizing photography in research has been used both with children and adults but in the context of this thesis, it is discussed from children's perspective. In photo elicitation, the researcher provides minimal guidance giving children the power to determine which pictures to take (Dedding, Schalkers and Willekens, 2012). Thus, photographs provide a direct look into children's experiences (Carter and Ford, 2013). Photographs can serve as representation of the experiences which might not be easily articulated in other ways (Clark, 2005).

Pictures taken during the photo elicitation research are not intended to stand alone (Carter and Ford, 2013). Instead, the photographs are used as a starting point for a subsequent interview in which the participant provides a verbal description about them (Driessnack and Furukawa, 2012). It is important to respect the participant's own interpretations of the photographs and not to unthinkingly override these with researcher's own analysis (Carter and Ford, 2013). In the interview, participants are usually asked to explain what a particular picture represents and why they decided to take that picture (Punch, 2002). The interview should be guided by open-ended questions and clarifications should be asked when needed (Mandleco, 2013).

There is a number of benefits to using photography in research with children. It increases children's attention span by capturing their attention for a longer period (Dedding, Schalkers and Willekens, 2012). It also helps to build rapport between the researcher and the child and gives structure for the interview (Fargas-Malet et al., 2010). Photographs can also reduce possible verbal obstacles, trigger memories, and produce unpredictable information (Dedding, Schalkers and Willekens, 2012; Hurworth, 2003). Photographing is fun and enjoyable for children and does not require any specific abilities (Punch, 2002).

Using photography in research possesses also some disadvantages. It may lead participants to focus only on visible and observable phenomena rather than abstract concepts (Bugos et al., 2014). Confidentiality is difficult to obtain since everyone in the pictures should give an informed consent (Fargas-Malet et al., 2010). Punch (2002) also mentions that child participants may not deliberately consider what to photograph, but take pictures of spontaneous events leading to an over-emphasis of importance for that particular moment. Moreover, children may take photographs over a short time period rather than over the longer period requested (Mandleco, 2013). Bugos et al. (2014) had also encountered a problem that young participants take more self-portraits than actual photographs of their environment.

Participatory methods are still uncommon and not well accepted in hospital context (Carter and Ford, 2013). According to Schalkers, Dedding and Bunders (2015), this is due to the ideological clash with participatory and medical paradigms. However, researchers see potential in participatory methods and suggest to employ them in evaluating hospital care with children (Schalkers, Dedding and Bunders, 2015).

3.3 DESCRIPTION OF THE INSTRUMENT

An initial prototype of the research instrument was developed to be tested in the empirical study. As children lack the capability of hypothetical thinking and understanding abstract concepts (Piaget, 1988), a high-fidelity, functional prototype was created. Special care was taken to develop the prototype to be as child-friendly as possible. Reading skills are not required and icons are exploited. Fun is an important attribute in children's programs (Punch, 2002), and thus, the instrument has a colorful user interface. The instrument supports children's 'here and now' characteristics by encouraging children to photograph issues as they encounter them (Kortesluoma, Hentinen and Nikkonen, 2003).

The instrument is an Android application designed for a tablet device and it focuses on making the photo elicitation as easy as possible, especially from the patient's perspective. The instrument was implemented by a software company. LAPSUS research group, especially the author of this thesis, collaborated with the company to plan and specify the functionalities and interactions of the instrument. The user interface is in Finnish since it is the language of the empirical study.

Table 5 lists the features included in the application prototype. Taking positive and negative photographs and viewing them are the primary features. Additionally, the prototype supports creating separate profiles for individual patients.

Table 5: Features in the research instrument

Feature	Description
Taking photographs *(primary feature)*	Participant first chooses the type of picture they want to take (things I like / things I do not like / self-portrait) by tapping an icon and then, takes a photograph.
Viewing photographs *(primary feature)*	Pictures are shown in a list and the number of each type of photographs is indicated. Individual photographs can also be opened to full screen.
Creating a profile	Each participant can be created their own profile, where their photographs are saved. A password is required to access the photographs taken by other participants.

Two identical Samsung tablet devices were used in the empirical study. They were set up in a way which restricted children to use only the photographing application. When a participant unlocks the device, the application automatically opens on the participant's own page (see Figure 5). At the top of the page, participant's profile information is presented. This includes participant's profile picture, name, age, and the length of stay in the hospital. Below, the photographs are listed together with an indication of the amount of each type of pictures. The photographs are organized into three categories: 'things I like', 'things I do not like' and 'self-portraits'. At the bottom of the page, buttons for taking photographs are displayed.

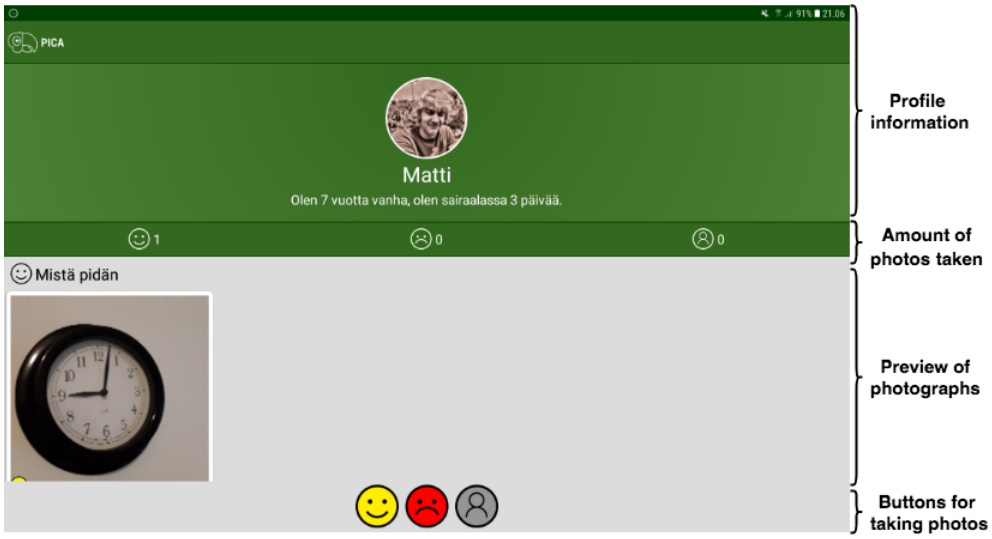

Figure 5: User interface of the instrument prototype

In the next chapter, the actual use of the instrument as part of the empirical research is described in more detail. Besides answering the research question of how suitable the photo elicitation technique is for measuring children's patient experience, the empirical study served as a user testing providing useful input to guide the future development of the instrument.

4 METHODS AND DATA

This chapter describes how the empirical research was conducted. The aim of the empirical study was to answer the research question of how suitable the photo elicitation technique is for studying children's patient experience. The chapter is divided into four parts. First, the data sources and the participants are described (4.1). Second, the methods used for collecting the data are explained (4.2). Third, the data analysis process is presented (4.3) and lastly, ethical considerations are addressed (4.4).

4.1 DATA AND PARTICIPANTS

The empirical data of this thesis consist of a qualitative photo elicitation study participated by eight pediatric patients. The purpose of collecting the data was to test the photographing instrument with child patients and gather information about children's patient experience. The empirical research sessions were recorded with the participants' permission and transcribed verbatim. All the empirical data are in Finnish.

The data were collected during August 2017 in two different units of Children's Hospital in Helsinki: Day Hospital and Rehabilitation Unit. These units were selected for the study because they provide care only for pediatric patients with long-term illness. Day Hospital treats child patients from different specialties, such as organ transplantation patients and cancer patients. Rehabilitation Unit provides care for physically or multiply disabled children and adolescents. Both in Day Hospital and Rehabilitation Unit, patient's visit can last for multiple days but they do not stay overnight in the hospital.

The data contain 64 photographs together with transcripts and recordings from the photo elicitation interviews. The interview data include three themes: (1) participants' descriptions of the photographs, (2) participants' favorite and least favorite photographs, and (3) children's and their parents' feedback about the study. A summary of the empirical data used in this thesis is presented in Table 6.

Table 6: Empirical data collected from pediatric patients (N = 8)

Data type	Themes	Amount
Photographs	- Positive experiences in hospital - Negative experiences in hospital	N = 64
Interview transcripts & recordings	- Description of the photographs - Selecting the favorite and the least favorite photographs - Feedback about the study	53 pages & 133 mins

Pediatric patients were chosen to the study through purposive sampling. The nurse managers of the selected units scrutinized the appointments made for August and listed the children who fit the criteria. The criteria for participation was that the child (1) was aged between 6 and 10 years, (2) had been diagnosed with a chronic illness, (3) was staying at the hospital for at least one full day during August 2017, and (4) was able to speak Finnish.

Altogether, eight children participated in the photo elicitation study individually. In this point, the saturation was reached as the themes of the photographs and interviews started to repeat themselves. Five of the participants were studied in Day Hospital and three in Rehabilitation Unit. The participants were aged between 7 to 10 years and thus, the actual age range was one year smaller than in the criteria for participation. The time period available for children to take photographs varied from one to three days, depending on the length of the stay at the hospital. One family who was asked to participate refused to take part in the study. Further information about the participants is provided in Table 7.

Table 7. Description of the participants in the photo elicitation study

ID	Hospital unit visited	Gender	Age	Length of stay
1	Day Hospital	Girl	10 yrs.	3 days
2	Day Hospital	Girl	10 yrs.	2 days
3	Day Hospital	Girl	10 yrs.	1 day
4	Day Hospital	Boy	8 yrs.	1 day
5	Day Hospital	Boy	7 yrs.	2 days
6	Rehabilitation Unit	Girl	8 yrs.	2 days
7	Rehabilitation Unit	Girl	8 yrs.	1 day
8	Rehabilitation Unit	Boy	7 yrs.	2 days

The nature and the course of the photo elicitation interviews varied. Some children were shy and quiet and they needed to be more encouraged to describe their experiences. One child was reluctant to discuss about the photographs, and the parent and the nurse had to present the pictures to the researcher. On the contrary, some other children were talkative and excited to tell about their stay in the hospital. Also, the extent of the parents' involvement in the discussions varied: some of the parents focused only on listening, whereas others participated more in the conversation. Thus, the explanations of the photographs varied in their particularity and extent.

4.2 DATA COLLECTION

The photo elicitation study included four steps, which are visualized in Figure 6. Before arriving at the hospital, potential families were contacted by phone to inquire their willingness to participate in the study. They also received written information about the study via email (see Appendix 1: Research information leaflet and Appendix 2: Instructions for the participants). With one participant, this was not possible, because their hospital stay was confirmed so late. In this case, information about the study was provided in the hospital at the arrival of the family.

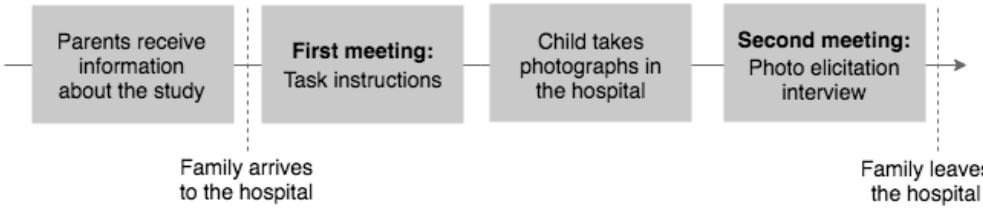

Figure 6: Steps of the photo elicitation study

The researcher met each of the participants twice: soon after they had arrived at the hospital and before they were discharged. The exact meeting times were arranged together with the family and the hospital personnel in order to find the most suitable timeframes. The author of this thesis was present in all of the sessions as a researcher, and the children attended together with their parents. Special attention was given to ensure that the research sessions would not be weary for children who have limited attention span (Coyne, 2006). Hence, the discussions were kept concise; the first meetings lasted approximately 10 minutes and the photo elicitation interviews lasted 10 to 30 minutes.

During the first meeting in the hospital, general information about the research was revised and detailed instructions of the task were explained. The child was asked to take altogether ten photographs – five photographs of things, events or places they liked and similarly, five photographs of issues they did not like in the hospital. According to Bugos et al. (2014), ten photographs is a manageable set for an interview. The child was instructed that they can take photographs of anything they want, except other patients. As suggested by Kortesluoma, Hentinen and Nikkonen (2003), an effort was made to ensure that the child understood that the study was not a test and there were no right or wrong answers. A tablet device and a charger were provided to the child and the photographing instrument and its features were gone through. The child and their parents had also a chance to ask questions about the study. After ensured that all the information was understood, both the child and a parent provided a written consent of participation (see Appendix 3: Consent form for children and Appendix 4: Consent form for parents). Before ending the session, it was agreed when the researcher meets the family again to conduct the photo elicitation interview. This was also the deadline for the child to finish taking photographs.

After the first meeting, the family continued with their schedule at the hospital and the child could independently take photographs when they wanted. Figure 7

illustrates the research setting and shows one participant taking a photograph with the instrument.

Figure 7: A participant taking a photograph

The second meeting was the actual photo elicitation interview, and it was organized before the family left the hospital for home. This meeting was structured around three themes: (1) the child's descriptions of the photographs, (2) the child's selection of their favorite and least favorite photographs, and (3) the child's and their parents' feedback for the photographing study. An interview guide was created to offer a core set of prompts for encouraging child's storytelling (see Appendix 5: Photo elicitation interview guide).

The literature recommends that before starting the actual study, time should be dedicated to constructing a confidential relationship with a child participant (Kortesluoma, Hentinen and Nikkonen, 2003). However, since the child had already met the researcher once and they were somewhat familiar with each other, special effort to build rapport was not required. Nevertheless, the interview session started with a casual discussion of how the child's day had been and how they had experienced the photographing task.

After this, the photo elicitation started. The session was a co-constructive and non-threatening process, where the child was acknowledged as an expert on their experiences (Greene and Hogan, 2005). The child led the discussion and presented the photographs for the researcher in an order they decided. Pictures were undergone

individually and the child was encouraged to talk freely about them. As suggested by Mandleco (2013) and Punch (2002), 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, especially if the participant was reticent (Mandleco, 2013).

After all the photographs had been gone through, the child was asked to select a photograph, which represented the nicest thing in the hospital and respectively, a photograph of the worst thing in the hospital. As recommended by Mandleco (2013), the child participant was also asked if there was something they wanted to photograph but for some reason could not. In the end of the session, the child was asked for feedback about participating in the study. Their perceptions about the photographing task and the research instrument were collected. Their willingness to participate again in a similar study was also inquired. Additionally, feedback about the study was asked from the participant's parents.

A pilot study was conducted with one child before starting the actual research. The purpose of the pilot study was to test the photographing instrument, the research procedure, and the photo elicitation interview guide. The pilot study was not conducted in the hospital context, but it concerned the child's life at the summer cottage. The child was instructed to take altogether five photographs of things he liked in the summer cottage and five photographs of things he did not like. Necessary adjustments to the instrument prototype and the interview guide were made based on the pilot study.

4.3 DATA ANALYSIS

The analysis of the empirical data was conducted immediately after the data collection. The themes of the photo elicitation interview were used as a basis for the analysis and grouping of the qualitative data. The analysis was done in two phases. First, the photographs and their descriptions were analyzed to produce understanding of the pediatric patients' hospital experiences. Second, the insights and feedback on using the photographing technique were mapped. The perceptions of the child participants and their parents were analyzed and also the hospital personnel's and researcher's perspectives were scrutinized.

Before starting the actual analysis, the photographs were given individual names and the interview recordings were listened and transcribed verbatim. The transcripts were read through to form an initial understanding of the data.

First, the photo elicitation data were analyzed. As photographs taken during the photo elicitation are not intended to stand alone (Carter and Ford, 2013), the pictures themselves were not analyzed in detail. The focus was on the interview transcripts in which the children describe the photographs they took and give meaning to their experiences. Positive and negative hospital experiences were analyzed separately and thematically categorized. Participants' descriptions of what each photograph represents guided the categorization, but also the reasons for taking the photographs were noted. Similar issues from different interviewees were grouped together to identify themes. Information about the best and the least liked experiences was also analyzed, in order to identify possible regularities. During the analysis process, five positive categories and three negative categories emerged. These categories and their subcategories are listed in Table 8.

Table 8: Categories of the children's experiences identified during the analysis

Positive experiences	Negative experiences
Entertainment	**Medical care**
Toys in the hospital	Invasive procedures
Fun activities	Medical equipment
Digital entertainment devices	Others
Hospital facilities	**Hospital facilities**
Hospital canteen	Environment
Food	Others
Aquarium in the lobby	**Others**
People	
Hospital personnel	
Other people	
Medical care	
Others	

Second, the perceptions and feedback regarding the photo elicitation study were analyzed. The perspectives of different stakeholders – pediatric patients, parents, hospital personnel, researcher – were kept and analyzed separately. The interview transcripts were scrutinized and the findings and insights were summarized. Lastly, citations were chosen to illustrate the main findings regarding both the children's patient experience and the feedback of the study.

The analysis was conducted in Finnish since it was the original language of the interviews. The aim was to preserve the authentic expressions and language in the analysis process as long as possible. Only after the analysis was finished, the citations and their interpretations were translated into English for the reporting of the results. Thus, the original context and meaning of the answers were not lost during the analysis.

4.4 ETHICAL CONSIDERATIONS

When working with children and conducting research in a hospital context, it is essential to take into account the ethical considerations (Bishop, 2014). LAPSUS research project was granted an ethical approval from the Ethics Committee for gynecology and obstetrics, pediatrics and psychiatry at HUS. The approval was granted in August 2015 and it also covers this thesis.

Parents of the pediatric patients were approached in the first instance and whenever possible, their preliminary interest to participate was inquired on the phone prior the hospital visit. Information about the study was provided both in written and verbal formats. As suggested by Greene and Hogan (2005), special care was taken during the first meeting at the hospital to explain the instructions using age-appropriate language. Parents and children were assured of their right to withdraw from the study at any time. The confidentiality of the research sessions was articulated clearly and respected during the whole study. It was highlighted, that the data were handled anonymously and the study would not affect the care provided for the child by any means.

Children were regarded as competent actors, who were capable of deciding on their own participation. Thus, care was taken to assure that the children understood the aim of the study and were truly willing to participate. A specific consent form with age-appropriate formulation was created for children and written consent was obtained both from the children and their parents.

Inviting participants to take photographs in the study poses ethical challenges, especially if other people are being photographed (Fargas-Malet et al., 2010). In some studies, researchers have advised participants to request a written release form from each person in the photograph, while others have told participants not to take pictures of people at all (Bugos et al., 2014). In this study, children were instructed not to photograph other patients in the hospital and ask a verbal permission before taking a photograph of other people, for example, hospital personnel.

During the photo elicitation interview, special attention was given to protect the well-being of the research subjects. It was ensured that the study did not put a strain on the participants' health and that the participants had sufficient health condition to take part. It was also acknowledged, that for some children the participation can be an emotional and intrusive experience causing difficult feelings to arise (Ellingsen, Thorsen and Størksen, 2014). Children were given the power to lead the discussion and decide what they want to share with the researcher. As suggested by Mandleco (2013), the discussions were organized in a quiet room to avoid disruptions and ensure confidentiality. Parents were allowed to be present at the research sessions in order to prevent causing additional distress for the children.

As a reward and memento of the participation, children were given a set of photographs they had taken. To avoid coercion, children were not informed of the reward before they had finished the task. The data gathered during the study were stored securely and they were not available to anyone outside LAPSUS research group. During the analysis of the data, special caution was given not to impose inappropriate interpretations or adult assumptions.

5 RESULTS

This chapter introduces the key findings of the empirical photo elicitation study. Along with reporting the results, the chapter highlights examples of the photographs and citations from the interviews. First, the children's experiences portrayed in the photographs are studied (5.1). The positive and negative experiences are addressed separately. Second, participant's feedback on the research technique is presented (5.2).

5.1 CHILDREN'S EXPERIENCES IN THE HOSPITAL

As displayed in Table 9, the participants took more photographs portraying positive experiences than negative experiences in the hospital. The total number of positive photographs was 37, as the number of negative ones was 27. None of the participants took more than the requested number of ten photographs. As indicated with an asterisk in the table, 4/8 children took less photographs than requested and told that they either did not have enough time or they did not know what to photograph. Most of the participants who took less photographs than requested (3/4), were visiting the hospital only for one day.

Table 9: Number of photographs taken by each participant

ID	Length of stay	Number of positive photographs	Number of negative photographs
1	3 days	5	5
2	2 days	5	5
3	1 day	3*	3*
4	1 day	5	2*
5	2 days	5	5
6	2 days	5	5
7	1 day	4*	2*
8	2 days	5	0*
	Total	**37**	**27**

** Less photographs than requested*

Next, the themes that arouse from the children's photographs and interviews are described in more detail. First, the positive experiences are covered (5.1.1), and then, the negative experiences are discussed (5.1.2).

5.1.1 POSITIVE EXPERIENCES

The photographs representing children's positive experiences in the hospital fell into five main categories: entertainment, hospital facilities, people, medical care and others. The categories of entertainment and hospital facilities were photographed by the highest number of participants (5/8). The category of entertainment included also the most photographs, in total 13. Participants' favorite photographs were divided into four categories. 2/8 children had their favorite photograph in the entertainment category, 2/8 in the hospital facilities, 2/8 in the people category and 1/8 in others. One participant did not specify which photograph represents their favorite experience. Table 10 presents detailed information about the positive photographs. Next, each of the main positive categories is presented individually.

Table 10: Children's positive experiences categorized

Positive category	Frequency of participants	Frequency of photographs	Frequency of favorite
Entertainment	**5**	**13**	**2**
Toys in the hospital	4	5	0
Fun activities	3	5	2
Digital entertainment devices	3	3	0
Hospital facilities	**5**	**9**	**2**
Hospital canteen	3	4	1
Food	3	3	1
Aquarium in the lobby	2	2	0
People	**4**	**7**	**2**
Hospital personnel	4	6	2
Other people	1	1	0
Medical care	**4**	**5**	**0**
Others	**3**	**3**	**1**

Entertainment

Entertainment was considered as a positive issue in the hospital by 5/8 participants. In total, the participants took thirteen photographs related to entertainment. These photographs fell further into three subcategories: toys in the hospital, fun activities, and digital entertainment devices.

Children enjoyed toys in the hospital and many photographs were taken at the play areas. Four children took altogether five photographs of different toys: toy cars, car track, ponies and toy airplane (two photographs). It was common, that the toys were already familiar to the children and that they had played with those during their previous hospital visits. A parent of one child even mentioned that the child always looks forward to coming to the hospital in order to be able to play with their favorite toy.

> *"There are Pet Shop toys and that kind of airplane [in the photograph]." (Girl, 8 years old)*

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

Fun activities were photographed by 4/8 children and altogether five photographs were included in this category. Most of these issues portrayed arts and crafts that the children had done during their hospital visit. One child had decorated a canvas bag, one had made paper origamis and one had built a small box. Children liked that they could take their artwork home with them. Also, a piano was reported as a positive issue and photographed by one child. Fun activities were selected as the favorite thing in the hospital by two participants.

> *"This was the best! [...] [It was] a thing that you could use for folding all kinds of objects. I made that hat!" (Girl, 8 years old)*

Digital entertainment devices inspired 3/8 children to take in total three positive photographs. Television, video game console, and a mobile game were featured in these pictures. Playing games and watching movies were activities, which children told to enjoy.

> *"This is my favorite [mobile] game and I could play it here, too." (Girl, 8 years old)*

Figure 8 shows two examples of participant's photographs portraying the category of entertainment. On the left, there is a photograph of a play room and on the right, a mobile game.

Figure 8: Two photographs of the positive category of entertainment

Hospital facilities

Hospital facilities were photographed by 5/8 participants, who took altogether nine positive photographs of that category. The themes of the photographs were divided further into three subcategories: hospital canteen, food, and aquarium in the lobby.

Canteen was the most frequently mentioned positive place in the hospital. Three participants (3/8) took a total of four photographs related to the cafeteria. The photographs and the children's stories of them explained that variety of snacks are often bought from the canteen, which makes the children happy. One participant selected candy bought from the hospital canteen as their favorite thing during the hospital visit.

> *"And then I also got ice cream, my favorite ice cream!" (Girl, 10 years old)*

Hospital food aroused positive feelings in 3/8 participants, who took in total three photographs of food. Two pictures included lunch and one breakfast in the hospital. Children mentioned that the food tasted good and they enjoyed eating it. One participant selected food as their favorite thing during their hospital visit.

> *"[Reads comments on the photographs] Next one here says 'good food'. [It was] bread and that kind of stuff. I watched a movie at the same time." (Boy, 8 years old)*

> *"That food was good." (Girl, 10 years old)*

Two participants (2/8) took two positive photographs of an aquarium, which is placed in the hospital lobby. They mentioned that the fish in the aquarium was nice to watch and one child even told that they go to see the fish every time they come to the hospital.

> *"This is the aquarium. [...] It was right there downstairs. [...] [It was nice] because there was so much fish and such. I scored the picture with three smiling faces." (Boy, 8 years old)*

Figure 9 showcases two examples of participant's photographs representing the positive category of hospital facilities. The picture on the left portrays the hospital canteen and on the right, there is food.

Figure 9: Two photographs of the positive category of hospital facilities

People

Total of seven positive pictures of people in the hospital were taken by 4/8 participants. The main category of people included pictures of hospital personnel and one picture of another person.

Hospital personnel was photographed by 4/8 children adding up to a total of six pictures. Three of these photographs were portraying the children's personal nurses. Children appreciated the long-term relationship with the hospital personnel and characterized their personal nurses as familiar and nice. Other photographs included a physiotherapist, a dental nurse, and an ultrasound technician. To justify the pictures, children gave the persons the following attributes: fun, cheerful, friendly and fast. Most of the photographs of the hospital personnel (4/6 photographs) included the participant themselves. The children were posing with the nurse either

in a selfie or the photograph was taken by another person, usually the child's parent. Two participants selected hospital personnel as their favorite thing during their visit in the hospital.

> *"And well, here is my nurse. She has been taking care of me from the very beginning. [...] From the early times when I had an organ transplant. So, it was nice that she was familiar. [...] It is nice when you sort of know [the person] and such." (Girl, 10 years old)*

> *"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, 8 years old)*

> *"I'm just about to show you a photograph [of a physiotherapist]. She was a really nice nurse. [...] Well, she was really happy and yeah, she was funny and everything." (Girl, 10 years old)*

One participant took a picture of the researcher conducting the photo elicitation study. They told that they liked the photographing task and that the researcher was nice. Figure 10 presents two examples of participant's photographs representing the category of people. Both photographs portray nurses.

Figure 10: Two photographs of the positive category of people

Medical care

In total, 4/8 participants took five positive photographs of subjects related to medical care. The photographs portrayed physiotherapy (two pictures), blood pressure meter, electrocardiogram and pain relieving patches applied to child's hands before magnetic resonance imaging. These were among the children's positive experiences

because in comparison to other medical procedures they were characterized as easy, fast and painless.

> *"That [photograph] is from the physiotherapy where I went yesterday. [...] There was a lot to do and a nice kindergarten teacher." (Girl, 10 years old)*

> *Child: "H'm... This is my magnet resonance imaging."*
> *Parent: "What was applied on your hands?"*
> *Child: "Magic cream."*
> *Researcher: "Magic cream, okay. Why was it a nice thing?"*
> *Child: "Well, because it tickled." (Boy, 7 years old)*

Figure 11 includes two examples of participant's photographs representing the positive category of medical care. On the left, there is a photograph of a blood pressure meter and on the right, pain relieving patches.

Figure 11: Two photographs of the positive category of medical care

Others

Lastly, 3/8 children took three other positive photographs which did not fell into any of the previous categories. They represented a peaceful and quiet moment in the ward, watching an interesting scene of a construction site from the window, and going to McDonald's after the day in the hospital.

> *"There is that construction site. I took this [photograph] from the playroom where we were watching that." (Boy, 7 years old)*

Figure 12 shows two examples of participant's photographs representing the positive category of others. The photograph on the left portrays construction site and the one on the right, a peaceful moment.

Figure 12: Two photographs of the positive category of others

5.1.2 NEGATIVE EXPERIENCES

Negative photographs taken by the participants fell into three main categories: medical care, hospital facilities and others. The category of medical care was photographed by the highest number of participants (6/8) and included the most individual photographs (16 pictures). Additionally, all the participants who stated their least favorite experience in the hospital (6/8 participants), selected photographs from the category of medical care. Two children did not want to select their least favorite issue. More detailed information about the negative photographs can be found from Table 11. Next, the findings of each main category are presented individually.

Table 11: Children's negative experiences categorized

Negative category	Frequency of participants	Frequency of photographs	Frequency of least favorite
Medical care	**6**	**16**	**6**
Invasive procedures	6	7	4
Medical equipment	4	5	2
Others	3	4	0
Hospital facilities	**5**	**7**	**0**
Environment	5	5	0
Others	2	2	0
Others	**2**	**4**	**0**

Medical care

Subjects related to medical care were the most frequently photographed issues representing children's negative experiences in the hospital. Altogether, 6/8 children took sixteen photographs portraying this category. The pictures of medical care fell into three subcategories: invasive procedures, medical equipment, and others.

Invasive procedures were photographed by 6/8 children adding up to a total of seven photographs. The photographs portrayed cannula inserted in the back of the child's hand (five photographs) and issues related to taking samples (two photographs). Children mentioned that these invasive procedures hurt and are unpleasant. Also, some children explained that possible problems with the invasive procedures, make the event nasty. For example, blood sampling procedure can require many pricks to succeed or a cannula can get off during the night and need to be inserted again. Altogether, four children selected invasive procedures as their least favorite thing in the hospital.

> *"Well, this is when they inserted me a cannula and also, 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 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 again on the following day." (Girl, 10 years old)*

"Cannula. It's not nice when they take samples with it." (Girl, 10 years old)

Medical equipment was photographed by 4/8 children, who took in total of five pictures. The photographs included different appliances and supplies used for medical care: infusion pump (two photographs), magnetic resonance imaging scanner, ultrasound scanner, and a pack of disposable gloves. Children told that this equipment are related to procedures which are uncomfortable or restrict their normal activity. Two children selected medical equipment as their least favorite thing during the hospital visit.

"Here is this kind of apparatus [infusion pump]. You need to carry it with you and it's also quite heavy." (Girl, 10 years old)

"Gloves. More specifically, those gloves [points to the pack of disposable gloves]. […] With those, they take some kind of blood samples and stuff like that." (Girl, 8 years old)

"[Shows his hand] and that [points an infusion pump]. Why is some transparent liquid coming out from it? Isn't it so that it is coming out of that? [...] Yes, it hurts. Once, when I went there I cried terribly when they inserted that [cannula]." (Boy, 8 years old)

Altogether, 3/8 children took four photographs of other issues related to medical care. These photographs represented a hospital bed where a procedure was done, dentist's office, shower chair and a painful procedure of removing an adhesive bandage from skin.

"Well, they put a sticker on this [shows her hand] and when I ripped it off the skin turned red." (Girl, 10 years old)

"Well, I usually hate dentists. I was afraid if I have a cavity in there and things like that." (Boy, 8 years old)

Figure 13 includes two examples of participant's photographs portraying the category of entertainment. On the left, there is a photograph of a cannula and on the right, an infusion pump.

Figure 13: Two photographs of the negative category of medical care

Hospital facilities

Hospital facilities were photographed by 5/8 children, who took altogether seven negative pictures of the hospital surroundings. These photographs fell into two subcategories of environment and others.

Hospital environment inspired seven negative photographs taken by 5/8 children. These pictures included hospital bed (two photographs), patient room, toilet and the idea of not having enough privacy. Children characterized the hospital environment as boring, unsettled and sickly.

> *"It's quite annoying or such if there are other people in the same room. But now there's not. [...] Well, for example, if they see something or I don't know. [...] And if there are some small children and if they cry, it might start to annoy." (Girl, 10 years old)*

> *"That [toilet] was looking a bit nasty." (Girl, 8 years old)*

Other negative photographs of the hospital environment included pictures of hospital food and patient clothing. These were taken by 2/8 children.

> *"H'm, that kind of bad food. [...] It was like minced meat sauce and macaroni." (Girl, 8 years old)*

> *"Here is my pajama. [...] It is too big." (Boy, 7 years old)*

Figure 14 introduces two examples of participant's photographs portraying the negative category of hospital facilities. There is a hospital bed on the left and on the right, two chairs next to each other demonstrating the lack of privacy.

Figure 14: Two photographs of the negative category of hospital facilities

Others

Additionally, 2/8 children took four negative photographs which did not fell into any of the previous negative categories. These photographs represented the following negative experiences: waking up from anesthesia, the moment of leaving for a medical operation, and having to wait. One participant also took a picture of toys in the playroom and explained that all of them were targeted only for smaller children.

> *"I have also a picture from that playroom because there's not much to do for older children. Everything is only for small kids." (Girl, 10 years old)*

> *"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, 10 years old)*

Figure 15 shows two examples of photographs portraying the negative category of others. On the left, there is a photograph of the moment when a child had to wait for a long time; on the right a moment of a child leaving for an operation.

Figure 15: Two photographs of the negative category of others

5.2 PARTICIPANTS' FEEDBACK ON THE RESEACH TECHNIQUE

Children perceived the photographing task positively and 7/8 participants reported that it was nice to participate in the study. Respectively, 6/8 children said that they would do the photographing task again if they had a possibility, as 1/8 child said that they would consider it. One child did not tell their opinion about the participation. Children's feedback about the study was brief and the participants characterized the study mostly as nice or fun. One participant felt that participating was slightly stressful and one would have wanted a bit more time to accomplish the task.

> *"It was a bit stressful to take photos." (Boy, 8 years old)*

Most of the children (6/8) perceived it somewhat difficult to choose what to take photographs of. In total, 5/8 participants felt that positive photographs were easier to discover and in contrast, 2/8 perceived it easier to come up with negative photographs.

> *"Well, it was [difficult to think of what to photograph]. The things that I like were easy but the stupid things were a bit tricky." (Girl, 10 years old)*

Children's parents were also delighted by the photographing study and all of them (8/8) perceived it positively. They felt that photographing was an enjoyable activity for their children and participating in the study was overall a pleasant experience. Parents gave similar feedback with their children, and 3/8 of them confirmed that it was difficult to choose subjects to photograph. 2/8 parents also felt that their child would have needed more time to finish the task.

> *"It was something different for the basic life in the hospital. Quite a nice addition and brings something new to think about."*
> *(Parent of a 7-year-old boy)*

> *"A quite nice task. But I didn't really instruct him at all. He got to select by himself what to photograph and it was purely his choice. Personally, I would have probably taken much more negative photos."*
> *(Parent of an 8-year-old boy)*

> *"I got a bit amazed that it was a bit difficult to discover issues to photograph. But however, she managed to reach five photos of both types."*
> *(Parent of an 8-year-old girl)*

"It was a bit difficult for her to discover objects to photograph. And five photos felt quite much. There was a bit pressure to come up with photographs and then you had to even justify those."
(Parent of an 8-year-old girl)

"Really quite nice. If we had had a bit more time and didn't need to hurtle all the time, we could've thought more of what to photograph. But it was nice!" (Parent of a 10-year-old girl)

Some parents (3/8) reported that they occasionally reminded their child to take photographs. They felt that without their prompts, the child would not have remembered to perform the task. Additionally, 3/8 parents mentioned that the particular hospital unit was more positive by its nature compared to other units in the hospital. According to these parents, the visits to this unit include less unpleasant procedures and medical treatments than when visiting another hospital unit.

"Yesterday, I slightly helped her and asked whether she wanted to take photos of certain things. I felt that she wouldn't have taken any photos if I didn't prompt her a bit." (Parent of an 8-year-old girl)

"Both the good and the bad [photographs] were difficult to discover because it's just okay to be here. So, there's nothing totally bad or any best things. […] It's maybe slightly different compared to being on the ward. […] There the contrast is bigger and it's easier to tell what is really nice and what is really bad." (Parent of a 10-year-old girl)

All of the participants and their parents (8/8) said that they experienced no problems with the instrument prototype on the tablet device. Most of the families (6/8) did not have any additional feedback about the instrument itself. However, one child mentioned that using the device was difficult when a cannula was inserted to hand and one parent suggested that the physical size of the tablet device could be smaller.

"Maybe the tablet could be smaller. It might be a bit too big now because you have to carry it with you all the time."
(Parent of a 10-year-old girl)

"I got small problems with this hand [shows his hand with a cannula] because it really couldn't [use the tablet]. I felt like quitting but I wanted to take more photos." (Boy, 8 years old)

6 VALIDATION ON THE INSTRUMENT

This chapter uses the empirical findings to evaluate the research instrument and its applicability to the hospital context. The chapter contributes to the second research question and provides an answer especially to its sub-question: *How do children and their parents, hospital personnel, and researcher assess the use of the technique?* The participants' and their parents' feedback on the study was already addressed in the Chapter 5.2, so this chapter focuses on the perspectives of hospital personnel (6.1) and the researcher (6.2).

6.1 HOSPITAL PERSONNEL'S PERSPECTIVES ON THE STUDY

After conducting the photo elicitation study with patients, nurse managers from two hospital units, Day Hospital and Rehabilitation Unit, were interviewed. These interviewees are referred as "nurse manager 1" and "nurse manager 2". The interviews were semi-structured and aimed to gather the nurse managers' perceptions of the photographing technique and its applicability to the everyday work in their hospital unit. The data were collected during September 2017 individually at the interviewees' offices in Meilahti. These interviews included two themes: (1) evaluation of the usefulness of the photo elicitation data collected from pediatric patients, and (2) evaluation of the feasibility of the research technique.

An interview guide was applied to give structure for the discussions with the nurse managers (see Appendix 6: Interview guide for nurse managers). First, the interviewees were inquired of what kind of information they would want to have from children and what do they expect as the results of the photo elicitation study. Second, the results from the photo elicitation study were introduced. This was followed by a discussion about the feasibility of the research instrument and the usefulness of the data it provides. The interviews were conducted in Finnish and they lasted 35 and 45 minutes. They were recorded with the interviewees' permission and transcribed verbatim.

In principle, the interviewees considered it important to gather information from pediatric patients themselves. Both of them highlighted that the data gathered from children should be concrete and lead to practical improvements in the hospital unit. They elaborated that they wanted to know children's perspectives on issues which they were able to affect, such as the behavior of the hospital personnel or issues in the environment. They also mentioned that they wanted to validate their assumptions

and hear whether children's opinions differed from what they thought. Additionally, one nurse manager mentioned that they wanted information about how children felt that they are treated and whether they were afraid or in pain during their hospital visit.

> *"Probably something really simple which we can influence. [...] Something we can affect either with our own behavior or with the environment." (Nurse manager 1)*

> *"But then [we want to study] whether our thinking is correct and whether the current way of doing things is good." (Nurse manager 2)*

Before presenting the results of the photo elicitation study, the nurse managers were asked to guess which issues the children photographed. The positive photographs were assumed to include the following themes: hospital clowns, food, playroom, hospital personnel and the moment of leaving the hospital. Interviewees mutually presumed that the negative photographs would consist of medical operations, sampling and especially the procedure of inserting the cannula.

> *"And our people! I would assume that if they [pediatric patients] have visited here several times, they have got to know our employees and perceive them nice." (Nurse manager 1)*

> *"Inserting the cannula is probably the number one [worst thing] here. And also, taking blood samples." (Nurse manager 2)*

The nurse managers' assumptions proved to be corresponding with the actual results. Both of the interviewees felt that the children's photographs were mainly highlighting issues they already knew. However, there were also some more surprising results. Both of the interviewees were astonished that the children perceived some issues related to medical care as positive experiences. Additionally, one interviewee was surprised that entertaining activities were so frequently mentioned, and another interviewee did not assume that the role of the hospital personnel would be that big. The individual finding of unsuitable toys for older children attracted the interviewees' attention. Both of them mentioned that their units have tablet devices targeted for the use of older children and noticed that apparently, children are not well informed about the possibility use of those.

"I told you that the cannula would be the number one. That is something I knew already! [...] This [negative category of] medical care was totally foreseeable." (Nurse manager 2)

"Wow, really? I wouldn't have thought that. I still somehow understand [the photos of] the physiotherapy since each of our children goes there. But that these [positive experiences of medical care] come up. I'm astonished!" (Nurse manager 1)

"There's [no pictures of] iPads which we already have. Maybe at that time we didn't offer them and they [the children] didn't realize to take them." (Nurse manager 1)

Even though the nurse managers were already familiar with some of the themes that arose from the study, they both agreed that it is valuable to verify their assumptions. They emphasized that decisions should be done based on real data and not only on their gut feelings. However, one interviewee started thinking whether the results were providing information deep enough to be useful for their needs.

"Yes, we knew these [results] but surely you also have to validate them from time to time." (Nurse manager 1)

"Well, then it's not [useful] if [the results] don't provide any deeper information. [...] With this work experience – I have been working here for 30 years – I know quite well what they [pediatric patients] like and dislike here. I wonder whether the information is too shallow and serves me." (Nurse manager 2)

Both of the nurse managers had concerns about how the results are communicated inside the organization. According to them, some of the issues that arose from the study, such as unappealing hospital garments, should be tackled at the managerial level and not in an individual hospital unit. Thus, it was seen important that effective processes are created within the organization to transfer the findings to the persons in charge of that particular area.

"I think this tells how important the nurse's role is. I wish that this message would be delivered to the nurses as a compliment. But also, the message should go to the decision-makers to inform that this is an issue they should invest in." (Nurse manager 2)

The interviewees were dubious about the feasibility of the research technique for collecting children's experiences in their unit. Both of them wished that the technique would require as little effort as possible from the hospital personnel. They were concerned whether the procedure of meeting the patient twice and operating with tablet devices would take too much time and effort. Both of the interviewees highlighted that the nurses' work is already extremely hectic and they would not be willing to assign them any additional responsibilities or tasks. One interviewee mentioned that the data collection should fit the unit's current practices and be a seamless part of their everyday work. One of the nurse managers suggested that the unit's assistant could be facilitating the photo elicitation with the pediatric patients. The assistant could give the instructions of the photographing task at the reception when the family arrives, and briefly go through the photographs when the family is doing their check-out. The other nurse manager thought that there is no other option than to request the nurses to facilitate the data collection. The analysis of the photographs worried one of the interviewees and they highlighted that they would not have resources to conduct that.

> *"It [collecting data] should indeed be really automatic. Especially now, when [...] we should nurse more patients with smaller resources. In my opinion, it's unreasonable to demand [the nurses] to yet collect feedback." (Nurse manager 1)*

One nurse manager told that in their unit, they could conduct the photo elicitation study a couple of times a year, but they did not see it in a continuous use. The other nurse manager was eager to test the technique in practice if there was a possibility to conduct a pilot study, for instance. Both nurse managers agreed that if the process of the photo elicitation study was effortless, they could see it as a practical way of collecting data from children.

> *"Probably it wouldn't quite work as it is, I don't believe in that. If we want to use that kind of data collection method, I would somehow see that it needs to be periodic and not by any means continuous." (Nurse manager 1)*

6.2 RESEARCHER'S OBSERVATIONS AND EXPERIENCES

The researcher's observations and insights about the photographing technique were mapped to summarize the practical experiences of using the technique. Next, the experiences around the following themes are discussed: photographs taken by the

patients, conducting interviews with children, involving parents and using the tablet instrument.

The use of photography worked well with the majority of the children. All children were familiar with taking photographs and using electronic devices. Most were excited to get a tablet device and were eager to take photographs with it. The participants followed the instructions well and photographed positive and negative issues, just as requested. The children took photographs relatively evenly throughout their hospital visit, and only 2/8 participants took photographs mainly either at the beginning or at the end of their visit. Majority of the photographs portrayed things that the children experienced during their current hospital visit. However, 3/8 participants took also photographs of issues, which they had encountered during their earlier visits to the hospital and not during the current stay.

> *"This [photograph] portrays ponies which I sometimes play with. [...] This time I didn't [play with them] since I had a lot of other things to do."*
> *(Girl, 8 years old)*

As mentioned before, 4/8 children took less photographs than requested, and told that they either did not have enough time or they did not know what to photograph. However, one participant also told that they took some of the photographs just for the sake of reaching the requested number of pictures.

> *"And then we'll move on to the sad [photographs]. I just had to come up with something – anything that looks stupid. That [picture of a bed] is not even bad." (Girl, 8 years old)*

The interviews with children varied a lot in their nature and length, and the individual differences between the participants were big. Roughly speaking, 3/8 of the participants were shy and reticent, 2/8 were talkative and 1/8 did not want to collaborate or tell anything about the photographs. The interview sessions needed to be adapted to these differences and some of the children had to be more prompted to tell about their experiences than others. The extract below demonstrates one type of a challenging interview with a reticent child.

> *Researcher: "Okay. What is this?"*
> *Child: "Oh well... In one cabinet, there were these."*
> *R: "Okay. Where was that cabinet?"*
> *C: "There, h'm..."*

R: "Was it at this unit...? There at the playroom, you mean...?"

C: "Yes!"

R: "Okay, there. What was the nice thing in this cabinet?"

C: "Well, I don't really know."

R: "Was it those paintbrushes...? Or those paints...?"

C: "I don't know."

R: "Did you use them? Did you paint something?"

C: "Yes."

R: "Was it nice?"

C: "Yes."

R: "What did you paint?"

C: "Hmm, that kind of thing..."

R: "What kind of thing? What did it portray?"

C: "Mom can tell." (Girl, 8 years old)

Overall, using photographs in the interview was useful and made the situation more relaxed. One advantage of the photographs was that the children did not need to discuss directly with the researcher, but they could focus on the pictures instead. However, one disadvantage was that since children were given the power to lead the discussion and introduce the researcher with their photographs, the children tended to proceed too quickly. For 3/8 children it was difficult to pay attention to the researcher's questions since they wanted to already move on to showing next pictures. Also, the tablet instrument sometimes captured the children's full attention.

Most commonly, children succeeded well in introducing the content of the picture, but elaborating it further caused challenges for them. Majority of the children had at least some troubles justifying their photographs and telling why they selected to take the particular picture. Elaborating how negative issues could be improved was not successful with any of the children. Also, 1/8 had troubles identifying the nicest picture and 2/8 could not tell which of the photographs portrayed the worst thing in the hospital.

Researcher: "Why did you dislike this?"

Child: "I just did. I didn't like that bed at all." (Boy, 7 years old)

Occasionally, the children struggled with finding words to describe their experiences and in these cases, the help from the parents was useful and encouraging. Sometimes children's stories were also illogical from the adult's perspective and a few times the

child even remembered the events wrong and their parents had to correct their mistakes.

> *Child: "Okay. This is my first photograph. I noticed that there is a PlayStation behind that television."*
> *Researcher: "Okay. Have you used it?"*
> *Child: "No I haven't. Or I have used one at home, I have two PlayStations! PlayStation three and PlayStation four."*
> *R: "Wow, really? Do you ever watch television here?"*
> *C: "Yes, I've watched."*
> *R: "Did you watch it today or sometime earlier?"*
> *C: "I watched it today."*
> *Parent: "No you didn't. They couldn't get it working." (Boy, 8 years old)*

Despite these challenges, the interviews were useful and provided deeper information about children's experiences. Some of the photographs were more self-evident and it was possible to guess the broader idea of what the particular picture represents. For instance, by only seeing a positive photograph of a nurse, one knows that hospital personnel are apparently liked by the child. However, the child's explanation of the photograph provided a whole new dimension to the issue. They could, for example, elaborate that the nurse was nice in particular because she was their private nurse and they knew her in advance. Besides providing deeper information for most of the photographs, the interviews were essential for understanding some of the more complex pictures. For example, 5/8 children took some photographs representing abstract experiences, such as long waiting times or lack of privacy, which could not be directly seen from the photograph itself without hearing the participant's description.

The level of parents' participation in the discussions differed. Generally, the parents were instructed only to follow the discussion and not to intervene. In practice, the conversations were mainly between the researcher and the child with some additions from the parents. In 3/8 interviews, the parents did not practically participate at all and in 2/8 session the parents' involvement was relatively high. However, the parents' participation was generally useful and reassuring for the child. Many times, they assisted children to name their experiences or gave important details to help the researcher to better understand the child's story.

Child: "And here is this [shows a photograph]. That kind of thing was in the playroom."
Researcher: "What is that?"
C: "H'm, this was something which I was put in."
Parent: "This was a model of a magnetic resonance imaging device at the playroom. He went there for the first time and was nervous about it."
(Boy, 7 years old)

Child: "Here is this kind of apparatus. You need to carry it with you and it's also quite heavy."
Researcher: "What is it again?"
C: "Well, it's that kind of thing... Which gives that... We had to wait for that doctor for a long time."
Parent: "[It's an] infusion pump. And in a way, you are attached to it for a certain time and it yet limits what you can do." (Girl, 10 years old)

Child: "And then there is this."
Researcher: "Okay, what is it?"
C: "This is like that... It came from here and went there."
Parent: "It's [related to] the chromium examination. That apparatus has to be carried with you for a while. And that [examination] is done every year."
(Girl, 10 years old)

As mentioned earlier, the participants did not have any problems with the tablet instrument and they could not think of many ways to improve it. However, during the interviews, a few insights about the instrument was found. Although the participants were instructed not to delete any photographs, 2/8 of them reported to having done so. Using the instrument was easy for the children but the user interface has also some opportunities for improvement. For example, in the main view, the area for the pictures listed could be bigger to better support the reviewing of the photographs. Also, after a photograph has been opened to full screen, the transition to the next picture could be possible with a swipe gesture.

7 DISCUSSION

This chapter discusses the relationship between the theoretical literature and the results of this thesis. First, the results are contrasted with the patient experience literature to highlight main convergences and differences (7.1). Second, the suitability of the technique is addressed by comparing the empirical findings to the general literature about researching children and experiences (7.2). Third, the practical implications of the study and areas for future research are identified (7.3). Lastly, the validity of the study is discussed (7.4).

7.1 FINDINGS FROM THE PERSPECTIVE OF PATIENT EXPERIENCE

The results of the photo elicitation study suggest that the hospital experience of children is not invariably negative. Overall, the participants took more positive photographs than negative ones, and additionally, the majority of the children reported that it was easier to discover positive issues during the hospital visit. This finding corresponds with previous studies which show that children's positive perceptions in the hospital can outweigh the negative ones (Wilson et al., 2010; Carney et al., 2003).

In this study, negative photographs are clustered around three big themes, whereas positive photographs are distributed around five themes. This suggests that children are unanimous of the uncomfortable issues in the hospital (especially matters related to the medical care), whereas pleasant experiences divide the children. Also, both positive and negative experiences included a miscellaneous category of others, which demonstrates that the photo elicitation technique was able to capture children's unique experiences that were distinctive from the rest of the findings. Next, these themes representing children's patient experience, are discussed in more detail.

The importance of hospital environment and entertainment facilities arises both from the literature and the empirical results. The empirical findings demonstrate that children enjoy toys, activities and digital entertainment devices that the hospital provides for them. This finding is consistent with prior research (see e.g. Bone et al., 2014). Also, children's photographs emphasize the importance of individual places and items, which are distinctive to the Children's Hospital in Helsinki – for instance, the aquarium in the lobby and the hospital canteen. However, some features of the hospital environment are also disliked by children. Negative feedback on hospital

beds and lack of privacy are found both from the empirical data and the literature (Curtis et al., 2004).

A major category of children's positive photographs comprises of people, especially hospital personnel. This important role of social relationships during hospitalization is also found from the related literature. A study by Lindeke, Nakai and Johnson (2006) found that pediatric patients value positive relationships with hospital staff. The empirical data further indicate that children appreciate the familiarity of the hospital personnel and especially continuity between nurses. This is supported by the study from Curtis et al. (2004) who found that continuity of care is significant for children. The fact that many of the children's photographs with hospital personnel were self-portraits, yet underlines the closeness between pediatric patients and their nurses. However, as opposed to the prior studies, none of the participants took a photograph of their family members. Researchers report that the presence of family, especially parents, is essential for hospitalized children (see e.g. Forsner, Jansson and Sorlie, 2005). However, this aspect of patient experience did not arise in this study.

According to the literature, pain and discomfort together with physical treatments and symptoms are children's major concerns in a hospital (see e.g. Pelander and Leino-Kilpi, 2010). The empirical data support this. Medical operations and especially invasive procedures compose the biggest negative category found from the photo elicitation study. However, interestingly, issues related to medical care are also found from the positive photographs. This indicates that some of the medical procedures are considered easier and more painless than others and thus, children categorize them as positive experiences.

In addition to these aspects, prior studies on children's patient experience raise negative themes of being left alone (see e.g. Salmela, Aronen and Salanterä, 2011), fear of the unknown (see e.g. Bone et al., 2014), disruption to normal everyday life (see e.g. Coyne, 2006) and lack of information (see e.g. Pelander and Leino-Kilpi, 2010). However, these issues are not found from the empirical data. Reason for this could be that the participants' hospital visits were relatively short, from one to three days, and their parents were present in the hospital with them all the time. Thus, the children had their family constantly reassuring them and they did not need to go through anything alone. Another reason could be the issue mentioned by Bugos et al. (2014), who suggest that the use of photography might lead children to focus only on observable phenomena ignoring the abstract concepts. Since these themes found

from the literature are all abstract, this could possibly be the case. However, as discussed in Chapter 6.2, the empirical data also include some more abstract concepts, although they are fewer than the photographs representing concrete ideas.

To conclude, this study contributes to the existing literature on patient experience by identifying positive and negative factors affecting children's experiences in the hospital. Positive factors identified are entertainment, hospital facilities, people, medical care and others. Negative factors are medical care, hospital facilities and others. These empirical results largely support the findings from prior research on children's patient experience. Some minor dissimilarities were identified, but the key factors occur both in the empirical data and in the literature. In the future, more research is required to explicitly define the concept of children's patient experience and develop a model of the factors affecting to it. An area for future studies is also to link children's patient experiences with parents' experiences, and create a holistic perspective on the whole family's perceptions.

7.2 SUITABILITY OF THE RESEARCH TECHNIQUE

The empirical study demonstrates that the photo elicitation technique can be successfully utilized in a hospital context to gather information on children's experiences. From children's perspective, the instrument is inspiring and fun, which are important factors according to the literature (Punch, 2002). Respectively, from researcher's perspective, the instrument provides a way to access children's experiences in an indirect and child-friendly matter. Again, from the hospital's viewpoint, the instrument demonstrated to provide insightful information directly from the pediatric patients themselves. The research instrument and its suitability to the hospital context are further discussed next.

Emphasized in the literature, patient experience should be studied in a way it produces reliable, valid and usable data, which can be utilized in practice (Beattie et al., 2015). The empirical results undoubtedly provide a glimpse into the world of pediatric patients and enable both the nursing staff and the hospital management see the children's perspective. As found from the interviews, the nurse managers were already familiar with part of the empirical findings, but still considered it important to collect data to verify their assumptions and convey information inside the organization. The advantage of the technique is to have a systematic way to collect information about children's experiences. However, as a disadvantage, the

usefulness of the data that creative methods provide has been criticized already in the earlier studies (Punch, 2002).

A major concern of the nurse managers was whether the data collection would be too demanding and time-consuming for the hospital personnel and whether the effort would be worth it. Due to the challenging nature of small children as research subjects, child-friendly approaches should be prioritized (Ellingsen, Thorsen and Størksen, 2014). For example, questionnaires as an easy and relatively automatic data collection technique are not applicable with children. It needs to be acknowledged that if informative, valid, and useful data from children wants to be obtained, some effort and time should be dedicated to gather the data. Thus, appropriate resources need to be assigned for the patient experience studies. However, the practical deployment of the research instrument was not in the focus of this thesis, and thus these issues require further examination.

The photo elicitation technique provides information on the factors of children's patient experience, but it does not measure the level or score of the experience. In other words, the instrument produces qualitative information on what children like and dislike in the hospital. However, during the photo elicitation interviews, children were asked to elaborate whether positive or negative pictures were more difficult to discover. Children's answers to this question give a rough idea on the overall experience level. Still, the technique does not address the issue precisely. Hence, the photo elicitation data can be used to identify and address problems in the service (Beattie et al., 2015), but it does not necessarily support in comparing healthcare providers and benchmarking performance (LaVela and Gallan, 2014). In order to better answer to these needs, another complementary technique could be considered.

It could be questioned, whether the selection process for the research technique resulted in the best decision. It was a multiphase process, in which information was combined from a variety of sources: conducting a literature review on children and their experiences, scrutinizing related research and their methodological choices, interviewing medical experts and lastly, making an informed decision based on all this data. Due to the triangulation of data sources and the systematic selection process, it is reasonable to argue that the final selection was successful and justified.

A relevant question is also how the selected photographing technique affects the data that is obtained. As already discussed, the use of photography may lead the participants' focus on observable phenomena rather than abstract concepts (Bugos et al., 2014). However, the empirical data include some photographs of more abstract issues and it also involve participants' experiences from the past. These types of pictures form the minority, but they demonstrate that the use of photography does not fully disregard the abstract experiences. Moreover, since children's capability to abstract thinking is lacking in the first place (Piaget, 1988), the problem might not be entirely solved by selecting another research technique.

Another concern is whether the technique encourages participants to take pictures without deliberately considering what to photograph (Punch, 2002). This would lead to an overemphasis on subjects that are easily accessible. The empirical data include one case, where the participant reported to have taken photographs just for the sake of reaching the requested number of pictures. Thus, this possibility cannot be completely excluded and requires further examination.

As the literature proposes, using photography provided a good way to access children's experiences with minimal guidance from the researcher (Dedding, Schalkers and Willekens, 2012). Pictures worked as a good structure for the discussion (Fargas-Malet et al., 2010). As the participants' developmental stage suggests (Greene and Hogan, 2005), the children experienced some communicational difficulties. From adults' perspective, children's stories were sometimes illogical. The participants struggled with giving their reasons for photographs and demonstrated to be incapable to think hypothetically. Thus, requesting children first to tell about a photograph and then justify why they took it, proved to be too demanding for some of them. Furthermore, asking children to elaborate how things could be improved in the hospital found not to be reasonable regarding their developmental stage. Overall, children were demonstrated to be a challenging user group, as one child even refused to describe their photographs.

Since power difference is one of the major problems when studying children (Greene and Hogan, 2005), the participants were given possibility to lead the discussion and present their photographs to the researcher. In practice, giving power to children proved to be challenging. Most of the children were successful in deciding the order of presenting the photographs and describing what each picture represents. However, children's stories lacked in-depth information and

most commonly, the researcher had to ask several follow-up questions to thoroughly understand the idea behind each photograph. Thus, the role of the researcher's questions ended up to be notable. As suggested by Lamb et al. (2003), open-ended and non-suggestive questions were yet favored and perceived useful.

Even though Dedding, Schalkers and Willekens (2012) reported that photography is able to better capture children's attention, some participants had troubles focusing on the interview. Having the tablet instrument in their hands during the interview session seemed to distract some children and draw their attention away from the researcher's questions. However, individual differences between the children were significant and children's prevailing mood seemed to affect both the photographs they took and their behavior during the interview session.

The empirical findings show that the participants had troubles with taking the requested number of photographs during their visit. Firstly, a one-day visit was clearly too short for taking altogether ten photographs. Additionally, participants told that they perceived it difficult to come up with subjects to photograph, and their parents also reported that they had had to remind their children about the photographing task. Since it is important to refrain from putting a strain on the participants and causing them stress, these findings have to be considered carefully. Participating in the study and using the instrument should be as effortless as possible for pediatric patients. Thus, the assignment of the photographing task should be reconsidered – for instance, the participants could choose themselves how many photographs they want to take, instead of making them feel that they need to reach a certain number of pictures. Alternatively, the whole logic could be different: the tablet instrument could notify the participant when to take a photograph. As the participant receives a notification, they would take a photograph of the prevailing situation and report whether they like it or not. However, these changes in the logic of the instrument require further research.

Table 12 summarizes the strengths and weaknesses of the photographing technique. These insights merge the findings from both the literature and the empirical study.

Table 12: Strengths and weaknesses of the photographing technique

Strengths	Weaknesses
- Inspiring and fun instrument for children - Indirect way to access children's experiences - Requires minimal guidance from researcher - Photographs provide good structure for an interview - Serves as a systematic tool for collecting data from children - Provides insightful information for the hospital - Helps in identifying problems in the service	- The tablet instrument may distract child during the interview - Might lead the focus on observable phenomena - Might encourage taking pictures without deliberately considering - Requires some time and effort from the hospital personnel - Nursing staff may be already familiar with part of the findings - Do not provide information about the level of the overall experience - Do not well support benchmarking or comparing hospital performance

To conclude, this study contributes to the literature of child research by providing experiences of using photo elicitation technique for accessing children's patient experience. Despite the growing number of studies conducted in the field of patient experience, there is a lack of research that incorporates the pediatric patients themselves (see e.g. Wilson et al., 2010; Coyne, 2006). Also, there is a lack of suitable research techniques for obtaining children's perceptions (Singh, 2007; Horstman and Bradding, 2002). This thesis has theoretical implications on these areas but further research is also needed. For instance, research needs to be conducted to produce information, which supports the selection of the appropriate research approach and reveal the benefits and drawbacks of each technique.

7.3 PRACTICAL IMPLICATIONS AND FUTURE WORK

The practical objective of this thesis was to provide information about the use of the photo elicitation technique in the hospital context, gather information about children's patient experiences and give the hospital concrete suggestions on how to start collecting data about the perceptions of pediatric patients. Additionally, the

objective was to provide information on how to refine the research instrument prototype. This study provides perspectives that may help both HUS Children's Hospital and other pediatric healthcare organizations to pay attention to children's patient experience. Also, different actors can benefit from this study by getting insights on how to study children or design software for children's use.

Typically, children's patient experience has been studied through their parents, but in this study the actual child patients were approached. The study unveiled that children have unique perceptions which can be valuable for the healthcare organization. The positive photographs indicated that children value toys and other entertainment, good hospital facilities, friendly nursing staff and painless procedures. Respectively, the negative photographs emphasized the unpleasant nature of invasive operations and the hospital environment. These themes provide the hospital ideas on the issues which they need to pay attention to. In Chapter 7.1, the results are discussed in more detail from the perspective of patient experience.

The implications of this thesis provide general guidelines for supporting Children's Hospital to collect data about patient experience from the pediatric patients themselves. The topic provides healthcare organizations means to strive to improve their services, provide care responsive to children's needs and even to gain a competitive advantage (see e.g. Carrus et al., 2015; Forsner, Jansson and Sorlie, 2005). Recommendations for pediatric hospitals are the following:

- **Involve children in patient experience studies.** It is not sufficient to study patient experience only through parents or nurses of pediatric patients. Children themselves have unique information about their experiences. The data collection process does not need to be overwhelmingly complex and it can fit the current practices of a hospital unit. Data collection can be started first in small scale and expanded later.

- **Utilize photographs to gather information about children's perceptions.** Although participatory methods are still uncommon in the hospital context, they have a great potential to have children's voices heard. Photographs help children to express themselves and provide valuable information that can be utilized to improve care.

- **Make sure that the research is child-centered.** Keep the photo elicitation interview short in order to maintain children's attention. Let

children introduce the photographs themselves and describe the pictures in their own words. Focus on the 'here and now' issues and do not ask hypothetical questions.

- **Prepare for asking follow-up questions in an open format.** Do not expect that children tell everything spontaneously but take part in the conversation and invite participants to further elaborate their experiences. For example, the following questions were proved to be useful: *What is in the picture? What do you do with that? When and where did you take the picture? What was happening when you took the picture? What is the subject in the picture like? Have you experienced that many times? What is the positive or negative feature in that picture? Why?*

In order to effectively employ the instrument to the everyday routines in the hospital, more research needs to be done. Open questions that have not been fully answered in the course of this study are the following: *What are the practical processes and steps for using the instrument in a hospital unit? Who is responsible for each step and when and how are each of them completed? How are the data analyzed and the results put together for concrete improvement suggestions? How are the results communicated inside the organization?*

Additionally, the instrument should be tested with a broader group of participants in order to get experience on its applicability on more general use in the hospital. In the future, empirical research needs to be conducted in different hospital units, and with children who have other diseases, are at different ages, and go through different stages of the patient journey.

For the software company, the results of this study provide recommendations on how to improve the photographing instrument. These are the following:

- **Improve the reviewing of photographs.** Increase the size of the pictures on the listing page by, for instance, decreasing the size of the top banner when the page is scrolled down. Make it also possible to click the numbers indicating the amount of each type of photographs – the page should then scroll down to show those pictures. Additionally, when a photograph is viewed in full screen, allow swipe gesture for the transition to the next picture.

- **Consider if the instrument could be a smaller tablet device or if participants could use their own smartphones.** This would remove the need for the hospital to administer separate devices and spare patients' from having an additional device to carry with them during the hospital visit.

- **Investigate whether the instrument could support children annotating the photographs independently.** This would save hospital personnel's time, and make the data gathering more automatic and effortless. The instrument could enable children for example to add comments, icons, ratings or voice recordings that describe the photograph. However, take children's developmental phase into consideration and conduct empirical tests and usability studies with the actual users before launching the instrument.

Besides the perspectives listed above, the underlying workings of the instrument should be investigated further. It requires more research to define the appropriate number of photographs, which participants are instructed to take. In the future, it should be also tested whether it would be less stressful for participants if the instrument prompted them to take a photograph instead of participants having to reach a predetermined number of pictures. An additional idea for future work is to investigate how the instrument could be designed so that it provides novel results also for the nursing staff. Lastly, it should be considered what is the reward for participants for taking photographs and whether photographs could serve as an empowering hospital memento for children.

7.4 VALIDITY OF THE STUDY

The validity of qualitative research can be evaluated using a variety of approaches. This thesis applies four judging criteria proposed for assessing interpretative research work: credibility, transferability, dependability, and confirmability (Guba and Lincoln, 1989). Next, these perspectives are briefly described and reflected upon the study.

Credibility addresses the internal validity of the study and involves establishing that the results are believable and the causalities are truthful (Guba and Lincoln, 1989).

To increase the credibility of the data collection, the interview guide for photo elicitation was tested in a pilot study and revised by one other researcher. After this, the interview guide was adjusted accordingly. During the study, it was acknowledged that children are vulnerable to external influences, and effort was made to promote credibility. However, it is possible that children's answers were affected by the researcher's phrasing of the questions or parents' presence in the research session. It was also taken into account that children are a challenging user group and can lie or exaggerate to appeal to adults (Punch, 2002). To further increase the credibility, voice recordings were also used to go back to the exact dictations and make sure that all details are persevered when analyzing the results.

It was acknowledged that using creative methods poses concerns about the reliability of the data (Punch, 2002). Furthermore, in one photo elicitation interview, the researcher had to rely on the nurse's and the parent's descriptions of the photographs since the child was reluctant to discuss about them. However, these photographs were relatively self-exploratory and the parents were able to provide the most essential information to support understanding the context of the pictures.

Transferability, parallel to external validity, is described as the extent to which the results can be generalized to other contexts or settings (Guba and Lincoln, 1989). As suggested by Guba and Lincoln (1989), this thesis aimed to provide a careful description of the time, place, context and culture of the study, in order to allow other researchers to assess the transferability of the results to other situations.

Due to the qualitative research approach, the results are not directly generalizable to other populations or universes (Guba and Lincoln, 1989) – in the case of this study, to other healthcare organizations, hospital units, or age groups. The empirical study had a limited sample of eight pediatric patients from two relatively similar hospital units at Children's Hospital. Moreover, patients with poor health condition were excluded from the study due to ethical reasons. Thus, positive cases maybe be over-represented and cause bias in the results.

To assess the usefulness and applicability of the instrument, two nurse managers were interviewed. Again, the sample size was small and thus, the findings are not generalizable to other units or staff members. However, the validity of the

instrument was further evaluated in a workshop organized by LAPSUS research group in Helsinki in October 2017. The workshop was participated by several healthcare professionals from HUS, patient experience researchers from Aalto University and Tampere University of Technology, and service design professionals from two companies. In the workshop, the key findings of this thesis were presented and the implementation of the instrument was planned. The perspectives gathered during the workshop supported the findings from the two interviews with the nurse managers.

Dependability refers to the consistency of the findings and the repeatability of the study. It concerns the coherence of the research process and independence from researcher's identity. (Guba and Lincoln, 1989)

One researcher from LAPSUS research group conducted the whole study. The researcher did not have medical background nor personal experiences of hospitalization. The positive side of these characteristics was that the researcher did not have any prior assumption on how it feels like to be in a hospital, which might have reduced her influence in the research situation. However, on the negative side, the lack of knowledge on medical issues might have caused misinterpretations of the data.

The dedication and close involvement of one researcher in the study provided a possibility to be fully absorbed in the topic. However, this may have also influenced the decisions made during the study and the interpretation of the results. Hence, the results could be different if the data analysis was made by a separate researcher.

Moreover, when researching children, the researcher's skills and phrasing of questions play an important role (Kortesluoma, Hentinen and Nikkonen, 2003). However, as suggested in the literature, the interview situation was organized in a way that takes into account children's competences, vulnerability, and the unbalanced power difference between adults and children. Still, it is possible that the participants did not share all of their experiences with the researcher due to, for example, shyness or anxiety.

As described in Chapter 4, the data collection and analysis were conducted in Finnish. Special care was given to preserve the authentic expressions and language of the interviewees. After the analysis, the citations and interpretations were

translated into English. An effort was made to ensure that the original context and meaning of the answers were not lost during the data processing. However, it must be acknowledged that the translation process includes ambiguity and risk of accidental misinterpretations.

The entire course of the study, from selecting the research technique, developing the instrument and empirically testing it, was a systematic and consistent process which incorporated consulting of medical experts on multiple occasions. Hence, it can be argued that the research process was coherent and did not compromise validity.

Confirmability covers the objectivity of the results, meaning that findings are rooted in the data, and the data can be tracked to their sources. It means that the results of the study are free of bias, values, and prejudice. (Guba and Lincoln, 1989)

In this study, the confirmability was ensured by recording all the interviews and transcribing them carefully. Actual citations from the interviewees were provided in Chapter 5 to authenticate the empirical results. The citations allow the reader of this thesis to make their own interpretations of the data, and to reflect the conclusions made by the researcher.

8 CONCLUSIONS

This thesis was conducted as part of LAPSUS research project and it addressed the following research problem: *How can children's patient experience be studied in the pediatric hospital?* The problem was answered through two main research questions. Answers to the research questions and their sub-questions are briefly summarized next.

RQ1: Based on the literature, which research approaches and techniques are applicable for studying 6- to 10-year-old children's patient experience?

The first research question was answered through a literature review. The first sub-question was: *What are the special considerations when studying children and their experiences?*

Main characteristics of children as research subjects are that they have limited competencies, they are vulnerable, and there is a power difference between children and adults. Experiences, again, are personal in nature and always partly inaccessible for outside researchers. Patient experience, more specifically, is a complex and multidimensional concept and studying it helps healthcare organizations to improve their services.

These special characteristics of children and experiences have several implications for research. The applied research approach is recommended to be co-constructive, qualitative and individual, which gives power to the child, and focuses on 'here and now' issues. Using age-appropriate methods are suggested. Attention should be also given to build confidential, non-threatening research setting. Additionally, patient experience should be studied close to the care encounter and in a way that produces utilizable and valid data. The considerations when studying children and their experiences are recapitulated in more detail in Chapter 2.4 and in specific in Table 2.

The second sub-question was the following: *Which approaches and techniques have been demonstrated successful in researching children's experiences in a hospital context?*

Several research papers were scrutinized to investigate how children's patient experience has been previously studied. These methodological choices were

categorized into the following groups: using adults as proxies (as opposite to using children as informants), traditional methods (e.g. interviews and questionnaires) and creative methods (e.g. art-based techniques and ready-made prompts). Moreover, individual research techniques in these categories were evaluated and lastly, four technique candidates were chosen to be further examined: drawing, photographing, picture cards and mood cards. In this study, photographing technique was selected to be developed into an instrument and empirically tested with pediatric patients. For more detailed information, Chapter 2.3.1 introduces the research methods in prior studies, and Chapter 3 addresses the instrument selection and photo elicitation technique in specific.

RQ2: Based on the empirical study, how suitable is a photo elicitation technique for measuring children's patient experience?

The second research question was answered with the empirical study. The first sub-question was: *What kind of experiences can photo elicitation technique unveil from pediatric patients?*

The empirical photo elicitation study was able to provide information about the themes which affect children's patient experience in the hospital. The positive themes identified were entertainment, hospital facilities, people, medical care and others. Respectively, the negative themes were medical care, hospital facilities and others. Chapter 5.1 presents the results in more detail.

The second sub-question was: *How do children and their parents, hospital personnel, and researcher assess the use of the technique?*

The participants and their parents perceived the photo elicitation study mainly positively and described it being fun. However, some of them were concerned that it was difficult to discover issues to photograph. Also, participants staying in the hospital perceived one-day visit too short for taking the requested number of ten photographs.

The hospital personnel who were interviewed thought that it is important to get information about pediatric patients' views directly from children themselves. Some of the results from the photo elicitation study were already familiar to the hospital personnel, but they highlighted the importance of both validating their assumptions and communicating the results also to other parts of the organization.

The hospital personnel were concerned about the workload that is required to conduct photo elicitation studies on a regular basis at the hospital. Also, from the researcher's perspective, the photo elicitation technique provided a good way to access children's experiences with minimal guidance. Participants' feedback about the study can be found from Chapter 5.2. as the perspectives of the hospital personnel and the researcher are addressed in Chapter 6.

To conclude, there is a real need to start studying children's patient experience and engage children in studies pertaining to their care. As demonstrated in this thesis, photo elicitation technique provides a good way to study children's experiences. Utilizing photography is applicable and fun both from the perspectives of the patients and the hospital personnel.

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APPENDICES

APPENDIX 1: RESEARCH INFORMATION LEAFLET

TUTKIMUSTIEDOTE

Lapsiperheiden uudistuva sairaala - Potilaskokemus palvelupolkujen arvon kehittäjänä (LAPSUS) -tutkimushanke (1.1.2015 – 30.6.2018)

Lasten potilaskokemuksen mittaaminen valokuvausmenetelmää hyödyntäen

Aalto-yliopisto, HYKS-lastenklinikka, Tampereen Teknillinen Yliopisto sekä Turun ja Oulun yliopistolliset sairaalat ovat käynnistäneet tutkimushankkeen, jonka tavoitteena on ottaa mahdollisimman hyvin huomioon potilaiden kokemukset uusia sairaaloita ja erityisesti lastensairaaloita suunniteltaessa ja rakennettaessa. Hankkeen nimi on LAPSUS: Lapsiperheiden uudistuva sairaala – potilaskokemus palvelupolkujen arvon kehittäjänä. Tämä tutkimus on yksi osa LAPSUS–tutkimushanketta.

Pyydämme sinua ja perhettäsi osallistumaan tähän tutkimukseen, jonka tuloksilla uskomme olevan suuren merkityksen sekä Helsinkiin rakenteilla olevan uuden lastensairaalan, että myös muiden suomalaisten ja ulkomaisten sairaaloiden suunnittelussa.

Mistä tutkimuksessa on kysymys

Tutkimuksessa selvitetään keinoja, miten 6–10-vuotiaiden lasten potilaskokemusta voidaan mitata. Tavoitteena on kerätä tietoa valokuvausmenetelmän käytöstä ja soveltuvuudesta lasten kokemustiedon keräämiseksi.

Tiedonkeruu toteutetaan

1. Pyytämällä lapsipotilaita ottamaan valokuvia sairaalassa olonsa aikana
2. Keskustelemalla lasten kanssa heidän ottamistaan valokuvista ja haastattelemalla heitä kuvissa esiin nousevista teemoista.

Tutkimuksen kohteena ovat lastensairaalan asiakkaat eli lapsiperheet ja tutkimus keskittyy lapsipotilaiden kokemuksiin. Osallistujia etsitään lähinnä HYKSin lastenklinikan potilaista ja heidän perheistään. Tutkimukseen kutsutaan perheitä,

joiden lapsella on pitkäaikaissairaus, joka vaatii yöpymisen sairaalassa. Tutkimukseen pyritään saamaan mukaan noin 10 lapsipotilasta.

Tutkimuksen toteutus

Kaikki tiedonkeruu tehdään tutkijoiden ohjauksessa yhteistyössä hoitohenkilökunnan ja lasten vanhempien / huoltajien kanssa.

Lapsille tarjotaan kuvausvälineet, joilla heidät ohjataan ottavan valokuvia sairaalakokemuksistaan. Tämän jälkeen tutkija käy yhdessä lapsen kanssa valokuvat läpi ja lapsi saa kertoa asioista, joita hän kuvasi. Valokuvauksen ja sen pohjalta tehtävän haastattelun tavoitteena on kerätä tietoa lapsipotilaiden kokemuksista sairaalasta ja hoidosta. Lisäksi valokuvausmenetelmän soveltuvuutta lasten kokemusten keräämiseksi arvioidaan.

Tutkimus suoritetaan sairaalassa perheelle sopivana ajankohtana. Tutkimuksen tekevät Aalto-yliopiston tutkijat, mutta tutkimukseen osallistuminen sovitaan HYKS:n lastenklinikan tai Turun ja Oulun yliopistollisten sairaaloiden kautta.

Tutkimukseen osallistuminen

Osallistuminen on vapaaehtoista ja perustuu potilaiden ja heidän vanhempiensa halukkuuteen kertoa omista kokemuksistaan. Lasten osallistuminen perustuu aina hänen omaan ja vanhempien kirjalliseen suostumukseen.

Tutkimukseen liittyviin kahteen tapaamiseen, alkuohjeistukseen ja loppuhaastatteluun, on syytä varata aikaa 0,5–1 tuntia kumpaankin. Vanhemman on hyvä olla läsnä ensimmäisellä tapaamiskerralla, kun tutkimuksen ohjeet käydään läpi. Tämän jälkeen lapsen toivotaan mahdollisimman itsenäisesti valitsevan kuvauksen kohteet, ja ottavan niistä valokuvat annetulla kuvausvälineillä. Tähän käytettävän ajan lapsi saa itse valita oman kiinnostuksensa ja jaksamisensa mukaan. Loppuhaastattelussa vanhemman läsnäolo ei ole välttämätöntä.

Tutkimus toteutetaan aikavälillä 1.8.2017 - 30.11.2017.

Osallistujalla on aina mahdollisuus keskeyttää osallistumisensa tutkimukseen. Keskeyttäminen ei vaikuta millään tavoin lapsipotilaan hoitoon. Keskeyttämistä ennen saatuja tutkimustuloksia voidaan käyttää hyväksi tutkimuksessa.

Tutkimukseen osallistuminen on vapaaehtoista ja mahdollisesti aiheutuvia kustannuksia, esimerkiksi matkakuluja, ei korvata. Tutkimukset järjestetään sairaalakäynnin yhteydessä.

Tutkimuksen luottamuksellisuus

Tutkimuksessa koottu aineisto tallennetaan eri tavoin tulosten analysointia varten. Aineistoa käsitellään luottamuksellisesti. Tutkimustuloksia ei voida yhdistää osallistujiin eli ne eivät sisällä mitään henkilö- tai tunnistetietoja.

Lisätietoja tutkimuksesta

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Tutkimushankkeen projektipäällikkö: tutkijatohtori Johanna Kaipio, Tietotekniikan laitos, Aalto-yliopisto, puh. 050 593 6822, johanna.kaipio@aalto.fi

Tutkimushankkeesta Lastensairaalassa vastaava lääkäri: Pekka Lahdenne, lastentautien dosentti, Lasten ja nuorten sairaudet, linjajohtaja, digitaalisten ja innovaatiopalvelujen linja, puh. 050 428 5521, pekka.lahdenne@hus.fi

APPENDIX 2: INSTRUCTIONS FOR THE PARTICIPANTS

Hei,

Hienoa, että olette vanhempiesi kanssa kiinnostuneita osallistumaan lapsiperheiden potilaskokemuksiin liittyvään LAPSUS–tutkimukseen. Lukekaa tämä ohjeistus läpi yhdessä vanhemman kanssa. Jos sinulle tai vanhemmallesi herää kysymyksiä tutkimukseen liittyen, voitte aina olla yhteydessä minuun (yhteystietoni löytyvät tämän tekstin lopusta).

Ohessa on tutkimustiedote, josta löydätte tarkempaa tietoa minkä vuoksi tutkimusta tehdään. Tutkimukseen osallistuminen on vapaaehtoista ja halutessanne voitte keskeyttää tutkimuksen milloin vain. Aineistoa käsitellään luottamuksellisesti ja tutkimustuloksia ei voida yhdistää osallistujiin.

Ennen tutkimuksen aloittamista sinua ja vanhempaasi pyydetään allekirjoittamaan suostumusasiakirjat. Mikäli haluatte tutustua niihin jo etukäteen, löydätte lomakkeet tämän viestin yhteydestä. Kun olette saapuneet sairaalaan, käymme vielä nämä ohjeet läpi yhdessä ja tällöin myös allekirjoitamme lomakkeet.

Tämän tutkimuksen tavoitteena on saada selville, mitä sinä ajattelet sairaalassa olosta ja miten kerrot siihen liittyvistä asioista valokuvien avulla. Tarkoituksena on, että tekisit valokuvaustehtävät itse. Jos joku asia on sinulle epäselvä tai tarvitset apua, voit kysyä vanhemmiltasi tai hoitajiltasi neuvoa.

Tutkimuksen aluksi tulen tapaamaan sinua ja vanhempiasi sairaalaan. Käymme läpi tutkimuksen ohjeet ja voitte kysyä kysymyksiä teitä mietityttävistä asioista. Tällöin sinulle annetaan valokuvauslaitteena toimiva tablet-tietokone, jolla voit ottaa valokuvia sairaalassa olosi aikana. Saat myös laturin, jolla voit ladata laitetta, mikäli siitä sattuu loppumaan akku. Sovimme myös, milloin tapaamme seuraavan kerran, jotta voit palauttaa tabletin ja esitellä ottamasi valokuvat.

Tehtävänäsi on ottaa 5 valokuvaa sellaisista asioista, jotka ovat mielestäsi kivoimpia sairaalassa ja 5 kuvaa sairaalan ikävimmistä asioista. Otathan tavallisia valokuvia etkä esimerkiksi videota. Voit ottaa nämä kuvat milloin vain sairaalassa olosi aikana. Muistathan kuitenkin ottaa kuvat ennen kuin tulen tapaamaan sinua toisen kerran! Voit itse vapaasti valita mitä asioita haluat kuvata. Ainoana

rajoituksena on, että muut sairaalassa olevat lapset eivät saa näkyä kuvissa. Hoitajista ja lääkäreistä saa ottaa kuvia, mutta tällöin on kohteliasta kysyä heiltä lupa ennen valokuvan ottamista.

Voit myös ottaa enemmän kuin vaaditun määrän kuvia, mutta muistathan lopuksi valita mitkä 5 kuvaa ovat kivoimpia ja mitkä 5 kuvaa ovat kurjimpia. Laitteella on paljon tilaa, minkä vuoksi toivonkin, ettet lainkaan poistaisi kuvia. Kuvia ei myöskään tarvitse muokata millään tapaa.

Ennen lähtöäsi sairaalasta tulen tapaamaan sinua uudestaan. Käymme yhdessä läpi ottamasi valokuvat ja saat kertoa minkälaisia asioita kuvasit. Tämä loppukeskustelu kestää noin puoli tuntia.

Kaikki tutkimukseen ja siinä käytettäviin laitteisiin liittyvät asiat käydään vielä läpi yhdessä ennen tutkimuksen aloittamista. Minulta voi lisäksi kysyä lisätietoja ja apua mahdollisissa ongelmatilanteissa. Näin ollen tarvetta monimutkaisten asioiden opettelulle tai muistamiselle ei ole.

Nähdään elokuussa!

Ystävällisin terveisin,

Hanna Stenhammar

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Lisätietoja tutkimuksesta myös

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APPENDIX 3: CONSENT FORM FOR CHILDREN

12.6.2017 v1.0

Lasten potilaskokemustutkimus:
Alaikäisen (6-10v.) lapsen suostumusasiakirja

Tutkimuksen nimi: Lapsus: Lapsiperheiden uudistuva sairaala - Potilaskokemus palvelupolkujen arvon kehittäjänä

Lääkärini tai aikuinen on pyytänyt minua mukaan tähän tutkimukseen. Minä sopisin tähän tutkimukseen, koska minua on hoidettu sairaalassa.

Tutkimuksessa selvitetään kuinka lapsia voitaisiin hoitaa paremmin sairaalassa. Tutkimuksessa kerron miltä minusta hoito ja sairaalassa käynnit tuntuivat. Joskus tutkija antaa minulle laitteen, jolla saan ottaa valokuvia. Myöhemmin juttelemme ottamistani valokuvista ja saan niiden avulla selittää minkälaista sairaalassa mielestäni on.

Lääkärini tai aikuinen on kertonut minulle tästä tutkimuksesta. Hän on kertonut, mitä tutkimuksessa tehdään. Olen saanut kysyä mieleeni tulleita kysymyksiä.

Lääkärini tai aikuinen on puhunut vanhempieni kanssa tutkimuksesta. Myös he ovat suostuneet siihen, että osallistun tutkimukseen.

Olen saanut kertoa, haluanko osallistua tähän tutkimukseen. Tiedän, ettei minun tarvitse osallistua, jos en halua.

Jos haluan myöhemmin lopettaa tutkimukseen osallistumisen, ei kukaan ole siitä minulle vihainen. Silloin minun pitää kertoa vanhemmilleni tai jollekin tutkimusta tekevälle aikuiselle, että en tahdo enää olla mukana. Lääkäri ja hoitajat hoitavat minua silti parhaalla mahdollisella tavalla.

Minuun liittyviä tutkimusasioita pääsevät näkemään vain minä, vanhempani ja tätä tutkimusta tekevät aikuiset.

Jos haluan osallistua tähän tutkimukseen, kirjoitan nimeni tähän suostumukseen.

Nimeni: _____

Päivämäärä: _____

Lääkärini tai
aikuisen nimi: _____

ja allekirjoitus: _____

Päivämäärä ja paikka: _____

Lapsus Aalto-yliopisto Perustieteiden korkeakoulu TAMPEREEN TEKNILLINEN YLIOPISTO HYKS OYS TYKS

APPENDIX 4: CONSENT FORM FOR PARENTS

12.6.2017 v1.0

Lasten potilaskokemustutkimus:
Alaikäisen (alle 18-v.) lapsen huoltajan suostumusasiakirja

Olen saanut tätä tutkimusta koskevan tiedotteen sekä suullista tietoa tutkimukseen liittyen. Olen ymmärtänyt tutkimusta koskevan tiedon ja minulla on ollut riittävästi aikaa harkita lapseni osallistumista tutkimukseen.

Tiedot antoi _____. Olen saanut myös esittää hänelle kysymyksiä tutkimuksesta. Myös lapsilleni on kerrottu tästä tutkimuksesta, ja hänen myönteinen mielipiteensä on selvitetty siten, kuin se hänen kehitystasonsa huomioiden on ollut mahdollista.

Tätä tarkoitusta varten annan luvan kirjata lapseni henkilötunnuksen sekä yhteystiedot. Tiedot kerätään ”Lapsus-hankkeen tutkimustietokanta” tutkimusrekisteriin. Tutkimustiedot käsitellään luottamuksellisina, sekä siten koodattuna, että lapseni henkilöllisyyttä ei ole mahdollista selvittää ilman tutkimusrekisterin ylläpitäjän vastuulla olevaa purkukoodia. Näitä koodattuja tutkimustietoja ei käsitellä Euroopan unionin alueen ulkopuolella. Annan suostumukseni, että edellä mainittuja lapseni tutkimustietoja voidaan anonyymisti käyttää myös muissa tätä aihealuetta koskevissa tutkimuksissa ja akateemisissa julkaisuissa.

Ymmärrän, että lapseni osallistuminen tähän tutkimukseen on vapaaehtoista ja voin perua tämän suostumuksen, ja keskeyttää hänen osallistumisensa tutkimukseen milloin tahansa ennen tutkimuksen päättymistä. Olen tietoinen myös siitä, että keskeyttämiseen mennessä kerättyjä tietoja käytetään osana tutkimusaineistoa. Tutkimuksen keskeyttäminen ei kuitenkaan vaikuta millään tavoin lapseni mahdollisesti tarvitsemaan hoitoon. Olen keskustellut tutkimuksesta lapseni kanssa ja kuullut hänen myönteisen mielipiteensä osallistumisesta.

Annan suostumukseni siihen, että lapseni osallistuu tähän tutkimukseen;

Lapsen nimi, syntymäaika ja osoite:

_____

_____

_____
Huoltajan allekirjoitus

_____ _____
Nimen selvennys Päiväys

Olen kertonut tästä tutkimuksesta tutkimustiedotteen mukaisesti sekä lapselle että hänen huoltajilleen (huoltajalle) ja otan vastaan tämän suostumuksen;

_____ _____ _____
Tutkijan allekirjoitus Paikka ja päiväys

_____
Nimen selvennys

Tätä suostumusasiakirjaa on tehty kaksi kappaletta, joista toinen annetaan huoltajille (huoltajalle) ja toinen arkistoidaan Lapsus-tutkimushankkeen toimesta.

Lapsus Aalto-yliopisto Perustieteiden korkeakoulu TAMPEREEN TEKNILLINEN YLIOPISTO HYKS OYS TYKS

APPENDIX 5: PHOTO ELICITATION INTERVIEW GUIDE

1. **ALOITUS**

- Jutustelu aluksi: Miten päivä on mennyt? Miltä valokuvien ottaminen tuntui?
- Agendan esittely: Käydään läpi valokuvat ja lapsi saa kertoa niistä
- Kysytään lupa nauhoitukseen

2. **VALOKUVIEN LÄPIKÄYNTI**

- Yleiskatsaus kuvista:
    - Kuinka monta kuvaa otit?
    - Oletko jo valinnut 5 kivointa ja 5 tyhmintä asiaa kuvissa?
    - Oliko helppo keksiä 10 kuvattavaa asiaa? Tuntuiko tämä paljolta vai vähältä?
- Minkä kuvan haluaisit ensimmäiseksi esitellä?
    - Onko tämä kiva vai kurja kuva?
- **Kuvan selitys:** Kerro tästä kuvasta? / Mitä kuvassa on?
    - *Jos lapsi on ujo ja aloitus on vaikeaa: Onko tässä kuvassa jotain mitä haluaisit kertoa minulle? / Minä en tiedäkään mikä tämä juttu tässä kuvassa on, voisitko sinä kertoa? / Minä näen tässä kuvassa odotushuoneen, onko se oikein?*
    - Jatkokysymyksiä esitetään, esim.
        - Muistatko missä otit tämän kuvan? Milloin?
        - Mitä kuvassa tapahtuu?
        - Joku esine: Mitä sillä tehdään? Onko sitä käytetty sinun hoitamiseen? Milloin? Miltä se tuntui?
        - Henkilö: Onko hän hoitanut sinua? Minkälainen hän on?
        - Paikka: Millainen tämä paikka on? Käytkö siellä usein? Miltä se tuntuu?
- **Perustelut kuvan ottamiselle:** Miksi valitsit ottaa juuri tuosta jutusta kuvan? / Mistä sinulle tuli mieleen valita kuvata tätä?
    - Mikä kuvan asiasta tekee kivan tai kurjan?
    - Kehitysehdotukset kurjista asioista: Tuleeko sinulle mieleen miten tämä olisi voitu tehdä toisin ettei se tuntuisi niin kurjalta?

3. YHTEENVETO KUVISTA

- Jos sinun pitäisi yksi kuva, mikä kuvaa sitä mikä sairaalassa on:
    - kaikista kivointa, niin mikä se olisi? Miksi?
    - kaikista tyhmintä? Miksi?
- Oliko sinulla mielessä jotain sellaista juttua, mikä on tosi kiva tai tyhmä täällä sairaalassa, mutta et jostain syystä pystynyt tai saanut ottaa kuvaa siitä?
- Poistitko kuvia tabletilta?

4. PALAUTE TEHTÄVÄSTÄ

- Mitä mieltä olit tehtävästä ja valokuvien ottamisesta? Miltä se tuntui?
- Oliko kuvattavien asioiden keksiminen helppoa?
    - Oliko kivoja vai tyhmiä asioita helpompi keksiä?
- Millaista tabletin ja valokuvaukseen tarkoitetun ohjelman käyttäminen oli?
    - Oliko käytössä ongelmia?
- Haluaisitko joskus uudestaankin tehdä samanlaisen tehtävän?

- **Vanhemman mielipide tehtävästä:** Miltä tehtävä vaikutti vanhemman näkökulmasta?

5. LOPUKSI

- Kerrotaan, että valokuvat saa muistoksi ja että ne lähetetään vanhemman sähköpostiin

APPENDIX 6: INTERVIEW GUIDE FOR NURSE MANAGERS

1. **ALOITUS**

- Agendan esittely: Käydään läpi alustavat tulokset + keskustellaan niistä
- Kysytään lupa nauhoitukseen
- Ennen tulosten esittelyä keskustellaan osastonhoitajan odotuksista:
    - Minkälaista tietoa lapsilta haluttaisiin?
    - Mistä arvelet lasten ottaneen valokuvia sairaalassa? Mistä he ovat pitäneet / mistä he eivät ole pitäneet?

2. **ALUSTAVIEN TULOSTEN LÄPIKÄYNTI**

- Tutkimuksen toteutuksen + osallistujien esittely
- Valokuvien positiivisten ja negatiivisten teemojen läpikäynti samalla niistä keskustellen

3. **TULOSTEN HYÖDYLLISYYDESTÄ KESKUSTELU**

- Onko lasten valokuvista nousseet teemat kiinnostavaa tietoa?
- Auttaisiko tämä tieto kehittämään sairaalan toimintaa?
- Minkälaisen yhteenvedon haluaisitte tuloksista?

4. **MENETELMÄN SOVELTUVUUDESTA KESKUSTELU**

- Kuinka sopivaksi arvioisit menetelmän tälle osastolle?
- Olisitteko halukkaita ottamaan menetelmän jatkuvaan käyttöön?
- Tarkempia teemoja esim.
    - Kuka olisi kokonaisvastuussa lasten potilaskokemustiedon keräämisestä?
    - Millaista tukea henkilökunta tarvitsee?
    - Miten tutkimus käytännössä olisi hyvä toteuttaa?
    - Miten/kuka analysoi tulokset?
    - Miten/kenelle tuloksia esitellään?

5. **TULEVAISUUS**

- Miten menetelmää pitäisi muokata, jotta se olisi mahdollisimman hyödyllinen ja sopiva teidän tarpeisiinne?