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Rights of the children in hospital care: Childhood, parenthood and family

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Rights of the children in hospital care:
Childhood, parenthood and family

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The purpose of this thesis was to provide information about parents' perception of the realisation of the rights of their hospitalised child, family-centeredness and ethical issues the parents experienced during the hospitalisation.

The study was done utilizing qualitative approach and by conducting semi-structured interviews for its eight participants. Data was analysed by using inductive data analysis method. The data was collected during the summer and autumn of 2014 from Helsinki University Hospital Children's Clinic, Lastenklินิกka.

Theoretical framework consisted of EACH Charter, a set of standards European Association for Children in Hospital has outlined based on United Nations' Convention on the Rights of the Child as well as literature and research done concerning family-centered care and family as part of the child's care.

The findings of this thesis showed that these participants did not perceive the rights of the children as fully realised in every situation while the child was in the hospital. To be able to participate in their child's care and the decision-making guiding it the parents needed to be empowered and guided by the health care professionals. The parents in this study also found it hard to see their own value as a co-carer and often felt that their input to care was small or even insignificant.

The realization of family-centred care was mostly hindered by physical environment and shortage of spacious single rooms where the whole family could stay. The participants expressed their hope that both of the parents and possibly even the siblings could be accommodated in to the same room with their child.

The ethical issues emerging from the data centred on ethical treatment of the child and the family, privacy and confidentiality. The treatment was mostly up to the staff and their professional conduct; the issues with privacy and confidentiality were in essence due to physical space and the challenges it posed.

From the New Children's Hospital parents hoped visible family-centeredness and more family-friendly facilities.

Keywords: hospitalisation, child, rights, family-centred care, parents

Anna-Sisko Sorsa

Sairaalahoidossa olevien lasten oikeudet: Lapsuus, vanhemmuus ja perhe

Vuosi 2014 Sivumäärä 68

Tämän opinnäytetyön tarkoituksena oli tuottaa tietoa vanhempien näkemyksistä koskien heidän sairaalassa olevien lastensa oikeuksien toteutumisesta, perhekeskeisyydestä sekä vanhempien kokemuksia eettisistä kysymyksistä sairaalassaoloaikana.

Tutkimus tehtiin hyödyntäen laadullista lähestymistapaa ja tekemällä puolistrukturoituja haastatteluja sen kahdeksalle osallistujalle. Aineisto analysoitiin käyttämällä induktiivista sisällön analyysiä. Aineisto kerättiin kesän ja syksyn 2014 aikana Helsingin Yliopistollisen Sairaalan Lastenklinalta.

Teoreettinen kehys koostui EACH -sopimuksesta, standardeista, jotka European Association for Children in Hospital on asettanut YK:n Lasten Oikeuksien Julistuksen perusteella, sekä kirjallisuudesta ja tutkimuksista, joita on tehty koskien perhekeskeistä hoitoa sekä perhettä osana lapsen hoitoa.

Tämän opinnäytetyön tulokset osoittavat, että nämä osallistujat eivät nähneet lasten oikeuksien täysin toteutuvan joka tilanteessa lapsen ollessa sairaalassa. Voidakseen osallistua lapsensa hoitoon ja sitä ohjaavaan päätöksentekoon vanhemmat tarvitsivat terveydenhuollon ammattilaisten voimaannuttamista sekä ohjausta. Vanhemmilla tässä tutkimuksessa oli myös vaikeuksia nähdä omaa arvoaan lapsen kanssahoitajana, ja he kokivat usein, että heidän panoksensa hoitoon oli pieni tai jopa merkityksetön.

Perhekeskeisen hoidon toteutumista haittasivat eniten fyysinen ympäristö ja pula tilavista yksityishuoneista, jossa koko perhe voisi yöpyä. Osallistujat esittivät toiveenaan, että molemmat vanhemmat ja kenties jopa sisarukset voisivat asua huoneessa lapsen kanssa.

Eettiset kysymykset, jotka aineistosta nousivat keskittyivät lapsen ja perheen eettiseen kohteluun, yksityisyyteen ja luottamuksellisuuteen. Kohtelu oli enimmäkseen kiinni henkilökunnasta ja heidän ammatillisesta käytöksestään; yksityisyys ja luottamuksellisuus olivat muodostuivat ongelmaksi lähinnä johtuen fyysisistä tiloista ja niiden asettamista haasteista.

Uudelta Lastensairaaltalta vanhemmat toivoivat näkyvämpää perhekeskeisyyttä sekä perheystävällisempiä tiloja.

Keywords: sairaalassa olo, lapsi, oikeudet , perhekeskeinen hoito, vanhemmat

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1 Introduction

The purpose of this thesis was to explore how the parents experience the realisation of children's rights and family-centred care during the hospital stay. This thesis takes special interest in themes that need to be attended to when planning for a the physical structure and care processes in the new children's hospital waiting to be built in Helsinki.

When exploring the rights of the children the researcher used the EACH Charter with its ten articles and annotations, as well as United Nation's Convention on the Rights of the Child (UNICEF 2013) as a theoretical framework. Family-centred care (FCC) is a model where those rights are put into practice, and is a part of the discursion in the area of children's rights in hospital. (Kelly, Jones, Wilson & Lewis 2012, 192).

United Nations established the Convention on the Rights of the Child (CRC) in 1989 and it has been ratified by all European countries (EACH 2006, 7). The aim of the convention was to promote child's right to be a child as opposed to being merely a small adult and thus needing special protection. (Lowden 2001, 101). By ratifying the Convention each county commits to promoting, enforcing and reporting the rights of the child in all areas of society, one of which is health care. (UNICEF 2005). The initial declaration has in turn made way for further steps in protecting children and childhood in different contexts. EACH Association (European Association for Children in Hospital) endeavors to promote children's welfare in hospitals. It has established standards or "Each Charter and Annotations" to guide professionals in ensuring that child's basic rights listed in the United Nations' convention are protected even in the event of their hospital stay (EACH 2006, 6).

NOBAB (Nordisk förening för sjuka barns behov) in Finland is the national association under the Nordic umbrella association, which has sprouted from EACH (mentioned above). NOBAB's main goal is to promote the NOBAB standards - initially same as EACH standards in a local level - by educating the hospital staff and parents. (NOBAB 2005).

The qualitative research was done by constructing semi-structured interviews for parents of children that are hospitalised and staying overnight in the Helsinki University Hospital in some of its paediatric units.

The working life partner in this thesis process was Helsinki University Hospital, Division of Women and Children. The prompt for this thesis came from several discussions with health care professionals involved in the planning the New Children's Hospital in Helsinki. More evidence-based information is needed when constructing new service processes that make the new hospital more child and family friendly.

2 Purpose of the thesis and research questions

The purpose of this thesis was to produce new knowledge on the experiences of the families of hospitalised children, particularly in regards to the realisation of the rights of children and family-centred care. The aim was also to find out what sort of other ethical issues in a the families may experience during their child's hospitalisation. The optimal outcome for this research would be to provide useful knowledge and perspective for the planning of the new Children's Hospital in Helsinki.

Helsinki New Children's Hospital is a nationwide project to build a new children's hospital in Helsinki University Hospital campus by the year 2017. As the vision of the new hospital is to be "the best children's hospital in the world*", particularly from the point of views of the patients and their families, it is important to include their opinions and experiences as early as possible in the project. (Lahdenne 2013).

Lahdenne stated in his presentation on the Children's Rights Day November 20th 2013, that one of the three main perspectives for the planning is the child's experience, particularly small child's, as they form the majority of the patient population in the current children's hospital. He also stated that Nobab-standards are written as fundamental criteria of the contracts between the Uusi Lastensairaala 2017 foundation, architects and the contractors.

The research questions were formed based on the literary review of the topic and the discussion with the representatives of the working life partner of this thesis. This thesis aims to answer the following questions:

1. How do the parents experience the actualisation of the rights of the child during hospitalisation in Helsinki University Hospital?
2. How do the parents experience the family-centred care during their child's hospitalisation?
3. What other ethical issues the parents experience concerning child's hospital care?

3 Theoretical background of the thesis

When going through the literature and the research done in the area of the child's rights in the Health Care setting, one can't help but run into a few recurring themes. Those themes are family-centred care, family participation and right for information. The themes are considered in the literature from both the parents' and the child's perspective and they often overlap.

According to the EACH Charter (EACH 2006), if the legal guardian is unable to stay in the hospital with the child, they should appoint another close relative or family member to do so in their stead. In this study, however, the interviewees were those parents with the legal guardianship to their child and who were expected to partake into the care and decision-making

3.1 Human rights as a principal of clinical care

Rights as a concept widely define our understanding of law and morality. Human rights are often considered to be at the very core of Western Civilization. It is used as a framework of sorts for morality and the idea of right and wrong. (Gorman 2003, 2).

United Nations' Declaration of Human Rights, made in 1948, has produced six different human rights treaties, one of which is UNICEF Convention on the Rights of the Child (CRC). The CRC was established after it was recognised that children need special protection, as they are more vulnerable and prone to harm and have specific needs in terms of development and overall wellbeing. (UNICEF 2005). CRC is the most widely ratified of UN Conventions and has enabled numerous positive steps in safe-guarding and protecting the rights of the children all around the world. (Shaahinfar & Betancourt 2014, 381).

World Health Organisation (WHO) has chartered a Declaration on the Promotion of Patients Rights in Europe (World Health Organisation 1994). It recognises that while the health care systems in many European countries have become more efficient and complex it also is in risk of becoming more hazardous and dehumanised. It is then important to put emphasis on the actualisation of the rights of each individual patient and increasing the quality of care. (World Health Organisation 1994, 5).

Nurses' responsibility to protect human rights and dignity can at times conflict with other rights and values that can also be considered important (Fry & Johnstone 2013, 132). International Council of Nurses ICN has published position statement where it acknowledges that if person's human rights are violated that can also harm their health and well-being. ICN has assumed a position that available, culturally acceptable and affordable health care is the right of all individuals without discrimination. (International Council of Nurses 2011,1).

Ivanov and Oden (2013, 235) mention "rights-based care" as a form of care that wants to ensure that human rights principles guide all care provided to patients, populations and communities. It helps the nurses to provide care that is not only good care but also reflects the UN's Declaration of Human Rights in all of its aspects (Ivanov & Oden 2013, 237).

From a legal standpoint in Finland, the health care professionals and providers are bound to follow The Act on the Status and Rights of the Patient (Finland 1992). It is a combination of legislation and ethical principles for different professional groups. The rights include civil

rights for patients as well as professional duties for the care providers. (Iltanen, Leino-Kilpi, Puukka & Suhonen 2012, 436).

Iltanen et al. (2012, 436) studied how well the Finnish nurses know the Act and what are their perceptions of the importance of said rights. They found that some parts of the Act are more familiar to the nurses than others; the right to good health care, treatment and access to care and right to self-determination being the best known parts. Although half of the nurses perceived their knowledge of the Act on the Status and Rights of the Patient as weak, it did not correlate with the actual results.

3.1.1 Charters promoting the rights of a child

This research began by getting acquainted with United Nations' Convention on the Rights of the Child (CRC). The Covenants have agreed to enforce and supervise the actualisation of the rights in all areas of society where children are involved. The CRC promotes the child's right to be protected from maleficence as well as their right to be a child. UNICEF, the United Nations' Children's Foundation, defines child as a person 0-18 years old. (UNICEF 2013). In this thesis this is how the child is defined, although the EACH Association points out that in many European countries only children up to 16 years of age are admitted to children's hospitals (EACH 2006, 9). This is most often the case in Finland as well.

EACH (European Association for Children in Hospital) held its first conference in Leiden 1988. At the conference the member associations agreed to a charter, which defined ten standard principles to be used in laws and regulations in each member state. (EACH 2006, 6). The standards are enforced on a national level by EACH's member associations. In Finland that is called "NOBAB in Finland" and it is a member of a Nordic Association "*Nordisc Förening för sjuka barns och ungas behov*", NOBAB. (NOBAB 2005).

The main reference point in this thesis is the EACH Charter as they are the basis of NOBAB standards and include annotations guiding the actualisation of the ten articles. NOBAB in Finland is an active participant in planning the new children's hospital in Helsinki and the NOBAB standards (or in effect, EACH standards) are the key principle to be considered when building a child and family friendly environment. (Lahdenne 2013).

The EACH Charter is listed below as it appears on the information booklet of the EACH Association (2006, 11-25). The annotations to the charter can be found on the original source of reference.

Article 1: Children shall be admitted to hospital only if the care they require cannot be equally well provided at home or on a day basis.

Article 2: Children in hospital shall have the right to have their parents or apparent substitute with them at all times.

Article 3: 1) Accommodation should be offered to all parents and they should be helped and encouraged to stay. 2) Parents should not need to incur additional costs or suffer loss of income. 3) In order to share in the care of their child, parents should be kept informed about ward routine and their active participation encouraged.

Article 4: 1) Children and parents shall have the right to be informed in a manner appropriate to age and understanding. 2) Steps should be taken to mitigate physical and emotional stress.

Article 5: 1) Children and parents have the right to informed participation in all decisions involving their health care. 2) Every child shall be protected from unnecessary medical treatment and investigation.

Article 6: 1) Children shall be cared for together with children who have the same developmental needs and shall not be admitted to adult wards. 2) There should be no age restrictions for visitors to children in hospital.

Article 7: Children have full opportunity for play, recreation and education suited to their age and condition and shall be in an environment designed, furnished, staffed and equipped to meet their needs.

Article 8: Children shall be cared for by staff whose training and skills enable them to respond to the physical, emotional and developmental needs of children and families.

Article 9: Continuity of care should be ensured by the team caring for children.

Article 10: Children shall be treated with tact and understanding and their privacy shall be respected at all times.

3.1.2 Rights of the hospitalised children

Children have been recognised as more vulnerable and fragile than adults and childhood as a meaningful part of person's life from 17th century onwards, but the approach to maintaining their "best interests" has changed significantly throughout the years (Lowden 2001, 101). "The best interest of a child" is, however, always been a somewhat problematic concept, as it can be viewed both from adult and child perspective (Söderbäck, Coyne & Harder 2011, 100). The adult point of view tends to be a protective one and often err on the side of caution. While it seeks to protect child from potentially harmful or upsetting information or from being forced to make too heavy decisions, it also conflicts with the children's right for self-determination in the issues concerning themselves and their right for information, which in

turn is the prerequisite for participation. (Coyne & Harder 2011, 313).

Another issue that comes up in the literature is closely related to both right for information and right for participation: the concept of competence. (Coyne & Harder 2011, 313). Competence is often perceived to be tied entirely to the child's chronological age or their general level of development, dismissing the child's individual level of maturity and understanding. While many of the hospitalised children are happy to leave all the decisions and discussions about their care to their parents, adults often do not give their child a chance to voice their opinion, either by withholding information or simply by not asking. (Söderbäck et al. 2011, 100; Kelly et al. 2012,197).

Lowden's (2001, 105) article from several years back also discusses the matters of child maturity and autonomy. The author points out that child's individual experiences (e.g. long-term illness) may have much greater effect on his or her level of competence than child's chronological age does, and should be taken into consideration when making a judgement on how much the child should be involved in his or her own care.

Parents have the legal right for information and participation concerning their child's care as their guardians. However, it does not necessarily mean that their right for decision-making should be more or less significant than their child's inherent right of information and participation concerning their own care - even if there is a conflict of opinions between the adults of the family, the child and the health care provider. (Kelly et al. 2012,198-199). The difficulties often arise when the health care professional or the parent or both deem the child to be incompetent due to his or her age or level of general level of development and thus feel that they can overrule or ignore the child's opinion. (Söderbäck et al. 2011, 101-102).

Söderbäck et al. (2011, 100) point out the UNICEF's stand on the Convention on the Rights of a Child that children need to be "encouraged and enabled" to make themselves heard in the matters concerning them by truly allowing the child participation. Kelly et al. (2012,198) state in their literature review that children's co-operation in their own care increases with the control that is given to them - in other words, the child that has been allowed some degree of autonomy is much more likely to co-operate with the care provided to him or her

3.2 Family participation

Child's right for his or her parent is written in the second Article of EACH Charter. (EACH 2006, 12). The theme of parent involvement can however be seen throughout the entire Charter, as something to be encouraged, supported and aided by health care staff. As found in the research done in Ireland by Migone, McNicholas and Lennon (2008, 411), the limitations related to hospital facilities often are the reason for why the parent is unable to stay in the hospital overnight. The parents, hospital staff and the children themselves feel, that the hospital

accommodations are not suitable for an extended stay of a family member. Parents and children also reported inadequate funds to be a reason not to be able to spend as much time together in the hospital as they would have wished. (Migone et al. 2008, 411).

Sousa, Antunes, Carvalho and Casey (2013, 24) studied parents' perspectives in negotiating their child's care in hospital. They found that the majority of the parents wanted to be able to participate in their child's primary care, even to be woken up during the night to do that. They were however sometimes hesitant to do so in fear of stepping over their boundaries. The parents in that study also perceived receiving information of their child's care as the most important thing and mostly felt that the staff was available for answers. (Sousa et al. 2013, 25).

Joanna Briggs Institute has produced a Best Practice information sheet for health professionals about parental participation in child's postoperative pain management. It states that the possible lack of participation is often due to the lack of information about the different pain management methods resulting in misconceptions and fears. (Stephenson, SiewHoon, Hong-gu & Mackey 2012).

There is still some dispute over matters such as should parents be allowed to stay during some smaller non-anaesthetic procedures. EACH Charter (2006,12) promotes parents involvement also in these situations, but for example Shields, Zhou, Pratt, Taylor, Hunter & Pascoe (2012, 5) suggest that not encouraging parents' presence in some small areas of care such as this, does not necessarily mean that the care is not family-centred as a whole.

Migone et al. (2008, 413) found in their study that staff, children and parents all agreed that the parents should be allowed to be present during the induction of anaesthesia. The authors also point to other studies, which show this procedure to be less traumatic for the child with the family member present during it.

Stephenson et al. (2012) find that being able to truly participate in their child's care the parents need information. It should be given at an appropriate time and in suitable portions to avoid overwhelming the parents. Stephenson et al. (2012) also state that parents, often unwittingly, use non-pharmacological methods of alleviating their child's pain, such as emotional support and focusing on the child's normal daily activities.

The health care system has come a long way from the times, when separating parents from their hospitalised children was seen not only normal, but beneficial for the child (Kelly et al. 2012,198). After decades of discouraging parents from visiting in the fear of distressing the child and affecting negatively in their care, it was discovered that long separation from their parents actually caused the children emotional trauma with long-term consequences (Shields et al. 2012, 3).

Although in most developed countries parents' visits in the hospital are unrestricted (Shields et al. 2012), there is still much variation in how the hospital visitation policies are enforced in each individual ward. (Smith, Medves, Harrison, Tranmer & Waytuck 2009, 40).

3.3 Family-centred care

Since the adoption of the EACH Charter in 1988 we have gained better understanding of what exactly is needed in regards to children as consumers of health care system. One of the most important findings has been the necessity of family-centred care as a model for child health care. (EACH 2006, 6-7).

The literature review by Foster, Whitehead, Maybee and Cullens (2013, 433; 444) defines family-centred care as a model of care that is planned around the whole family them being recognised as care-recipients instead of an individual child. The authors of the review found that on the occasion of hospitalisation will effect a change in priorities making the care of the child and preserving the family unit the most important things.

The concept of family-centred care in paediatrics has its foundation in the holistic approach to the child's overall wellbeing, which is perceived to be inherently tied to the family's wellbeing. By protecting the parents' constancy and influence in their child's life even during the hospitalisation and making them partners in care, the family can continue functioning well as a unit during the trying time of the child's illness. (Shields et al. 2012, 3).

Coyne, Murphy, Costello, O'Neill and Donnellan (2013, 471) conducted a survey amongst nurses and their perceptions of family-centred care in Ireland and found that whilst the nurses knew what it was in theory, implementing it into practice was far more difficult. Factors hindering the delivery of family-centred care were lack of knowledge, skill, time and resources.

Family-centred care is a quite commonly accepted approach particularly in paediatric health care, but, as it appears from updated literary review by Shields et al. (2012), variations in the execution can still be found all over the world. The model has its origins in USA and UK, based on the findings from 1950's, which resulted the increasing need for health care providers' to understand the child's emotional needs. The Platt Report from 1959 in UK recommended that the visiting hours for parents should be unrestricted and that the mothers stayed in the hospital with their child. This report was the initial push for the birth of family-centrec care concept (Shields et al. 2012, 3).

As the illness and hospitalisation of the child can itself be considered a great distress to the family unit as a whole, the EACH Charter 1 addresses particularly the appropriateness of the hospital admission (EACH 2006, 11). It states, that child should only be admitted to hospital if the care cannot be just as well provided in the home environment. In the research by Migone

et al. (2008, 413) majority of the informants, both staff and families, felt that the child was often admitted to the hospital unnecessarily. As this study was done in Ireland, it may not entirely reflect the situation in Finland, but does call into attention the financial and ethical aspects of care in general.

Although recognised in the most parts of the world being the most overall beneficial approaches to paediatric nursing, family-centred care model does not come without risks. While it promotes the family's active participation in the care of the child, the partnership between the health care provider, the parents and the child, it is when the views of those partners differ significantly when true problems occur. (Kelly et al. 2012, 198-199). According to Kelly et al. (2012, 198), it is often the adult votes that weigh the most. Health care professionals may be unsure as to how to handle the high distress and uncertainty of the parents, who in turn are desperately trying to find out what is in the best interest of the child, often with limited amount of information and understanding of the situation as a whole. (Kelly et al. 2012, 198-199).

Harvey and Ahmann (2014, 143) write about validation as a method of interacting in situations when there are confrontations between the health care provider and a family member. The purpose is not to validate the undesired behaviour, particularly if it is unsafe or aggressive, but to validate the feelings driving it. The aim of validating approach is to preserve fruitful and respectful communication even during conflicts and empower both nurses and family members, thus ensuring true connection between the parties and the actualisation of family-centred care.

While parents often are instrumental in the communication between the health care professionals and the child, it cannot be assumed that parent's or health care worker's view accurately reflects on what the child really experience or feel. In an ideal situation the negotiation of the care should be a holistic synergetic process involving child, parent, health care provider and the immediate support network. (Foster, Whitehead, Maybee & Cullens 2013, 433.)

According to Shields et al. (2012, 4), while the families may already be very distressed about their child's illness, they may also be expected to make decisions that they are not equipped to make. The study shows, however, that in health care units, which relied on parental involvement in the care of the child, parents were found to have inadequate information and understanding much less often than in the units with more traditional approach to care (Shields 2012, 12).

Migone et al. (2008, 414) found that around a quarter of the parents participating in their quantitative study felt that they would have wanted to be more involved in their child's care. The authors also mentioned, that the increased parent participation often leads to better

outcomes of care.

3.4 Ethical issues in family-centred care

While rights can be seen as important aspect of ethical care, there are still other issues that are important from particularly the family's standpoint. The United Nations Convention on the Rights of the Child (UNICEF 2005) states in its preamble that the family as a fundamental part of the society should be protected and assisted in fully assuming their place in the community. It is also stated that the child has the right to grow up in a family environment "with love and understanding".

International Council of Nurses (ICN) has established an ethical codex for nurses (International Council of Nurses 2012, 6) which among other things states that nurses are to provide care that respects human rights and ensure that the patients receive enough information in order to be able to make informed consent to care. Patients should also have right to choose or refuse care.

This may prove problematic to interpret when the patient is a minor; as can be seen from literature discussed previously, child's competence is often difficult to define and right for self-determination often violated for this reason. (Coyne & Harder 2011, 314). When the family is seen as a unit and inseparable part of child's life and well-being, it can perhaps be seen as an advocate for child's rights.

Tapp (2000, 79) found in her interpretive study of the relational ethics of family nursing that the nursing staff could at times dismiss the family's expertise of the patient and replace it with his or her own, possibly disregarding the family's more extensive knowledge of the needs, likes and dislikes of the patient. Tapp suggests commending as a method of empowering the family and engaging them in the care of their loved one. Exploring the story of the illness and the medical story from the patient's and family's perspective was also seen as helpful. (Tapp 2000, 79).

Foster et al. (2013, 457) found that the parents' trust in professional's decision-making compared to their own was authority directly correlated with how well they were informed. Communication, information and relationships all work together in creating the overall experience for the families and in effecting their satisfaction with the care.

4 Methodological background

As the purpose of this study was to explore the experiences of individuals on an emotional level, the qualitative method was the most appropriate to achieve the desired information. The reason for this is that qualitative research explores real life phenomena instead of trying to

provide detailed information. (Silverman 2005,7). Silverman also points out that qualitative study is a way to obtain a closer look on the “actor’s perspective”, in this case the parents’ (Silverman 2005, 10).

The purpose in this thesis was not only find out the opinions of the parents but also how they experienced and perceived things concerning their child’s hospital care. As the value of the findings lied in the insight it provided about the experiences and position of the parents who were participating, the data collection method was conducting semi-structured interviews. This method allows the researcher to both gain knowledge of the experiences of their informants, but also guide the interview in such a way that it helps to reach the purpose of the study. (Holloway & Wheeler 2013, 89-90).

4.1 Qualitative approach

This thesis was completed by using qualitative method. It is a method in which the researcher aspires to understand the phenomenon of interest as a whole by constant and on-going reflection of the data. The study design also shapes itself as the process goes along. (Polit & Beck 2010, 259-260). As the purpose of this thesis is to gain understanding of the experiences of the parents within their own contexts, a qualitative interview should provide me a platform for as non-restricted conversation with the participants as possible. (Bourgeault, Dingwall & de Vries 2010, 307-308).

Qualitative research has its place in healthcare research, as it offers holistic and human-centric view on the subject matter (Holloway & Wheeler 2013, 11). In this thesis the aim was to gain insight on the explicit and general experiences of the participants from the context they approached it, their reality. Holloway and Wheeler (2013, 12) also point out that particularly in health care research, the relationship between the qualitative researcher and his or her informant is based on trust and openness. This was one of the justifications behind choosing the qualitative method: the researcher’s idea was that it would bring forward more naturally emerging data about the true experiences as they were.

Polit and Beck (2010, 260) point out that typically, when using qualitative approach, the researcher needs to prepare for somewhat flexible timetable especially in data collection and analysis. In this thesis too the timetable went through some changes due to the challenges in data collection and personal matters. While in the end the study was completed by the time it was initially planned to be completed, the process did halt at times and the picked up the speed again. Particularly the data collection phase took much more time than was originally planned.

The qualitative research as a method requires an lot of planning and preparation before commencing the study, as the lack of time or extensive amount of data - or both - may prove

problems in the data analysis phase (Holloway & Wheeler 2013, 15). This proved to be true in this thesis as well. Facing the challenges of both the limited experience as a researcher and having rather tight time constraints, the process went through several unexpected obstacles, which, in hindsight, could have been avoided by planning more carefully ahead.

From qualitative philosophical context that people's experiences are always related to the context such as time or location or the mind set of the person in question (Holloway & Wheeler 2013, 26). According to Miles, Huberman and Saldaña (2014,10) a well-collected qualitative data offers a strong take on "real life". The challenge is, according to these authors, to find coherent descriptions while still not forcing the logic behind them. As the aim of this thesis was to gain very much real insight to the experiences and perceptions - whether based on correct or incorrect ideas - of the participants, it very much made sense to choose this approach.

4.2 Data collection

The data used in this thesis was collected by semi-structured interviews as it has been said to be one of the more effective approaches to find out person's subjective experience with a relatively small sample of participants (Silverman 2005, 112-113). The sequencing of the questions varies with each participant and depends on the process of the interview and the answers the participants give (Holloway & Wheeler 2013, 89). Semi-structured interview is conducted by having a list of topics or broad questions that are to be addressed in the interview, while encouraging participants to talk freely about them (Polit & Beck 2010, 341).

In this thesis the semi-structured interview was seen as suitable data collection method as the interest was laid in the true experiences of the participants and more structured method would perhaps kept the researcher from finding those out. (Bourgeault et al. 2010, 208). The researcher was, however, advised to provide more specific "sample questions" for each theme by the working life partner in order to obtain the research permit. Those sample questions along with the interview guide can be found in Appendix 1.

The themes for the interview emerged from the literature, particularly from the previous quantitative study conducted in Ireland by Migone et al. (2008, 411-412). They brought forward the main four themes from the ten articles of EACH Charter and were then further divided into different groups according to the phase of the hospital stay (admission and ward allocation, inpatient period, discharge and home care and general thoughts of time).

The subthemes in the study by Migone et al. (2008) combined the articles of EACH charter (EACH 2006) in the manner described below. (The Charter is listed earlier in chapter 3.1.1).

Articles 1 & 5: The child's admission to hospital should only be used as a last resort...Parents

and children have the right to be protected from unnecessary medical treatment and investigations.

Articles 2 & 3: The child has a right to their parent or parent substitute to be with them at all times...Parents should have easily available accommodation within the hospital setting.

Article 4: Parents and children have the right to be informed in the manner appropriate to their age and understanding.

Articles 6-10: Children should be cared for with other children who have the same developmental needs; they should have full opportunity for play, recreation and education while in hospital; they should be cared for by staff trained to work with children; they have the right to continuity of care by staff; they should be treated with tact and understanding at all times.

4.2.1 The participants of the study

There were eight participants in this study, and although the initial idea was to obtain up to 15 informants, the saturation point of the data was quickly approaching with eight participants and it was not seen necessary to obtain more interviews (Holloway & Wheeler 2013, 146). It also proved somewhat challenging to plan and arrange the interviews at the wards, even with the assistance of the nursing staff. Holloway and Wheeler (2013, 145) also indicate that in many qualitative studies sample size of 6 or 8 is sufficient when the group of participants is homogenous enough. As the researcher in this study interviewed members of a group sharing similar experience, their child's hospitalisation, the number of participants appeared to be large enough. (Holloway & Wheeler 2013, 139).

Of the 11 parents that were approached, eight were willing to participate. From some families the other spouse declined, but the other, who had been in a room when the study was introduced, was willing to participate. The researcher did not inquire for the reasons behind the refusal to take part in the study, although some spontaneously offered explanations, such as the emotional distress over the child's situation.

Two of the participants were fathers, other six were mothers. To protect their anonymity the direct quotations have not been distinguished between mothers and fathers. The average age of the participants was 32 years; ages varied between 21 and 51 years old. Two of the participants were unemployed at the time of the interview and five of them had received college level education or higher.

The ward managers of pediatric wards in HUS Lastenklänikka were approached via e-mail prior to commencing the recruitment of the participants. The purpose of the thesis as well as data

collection method were explained. Along with the attached thesis plan and research permit obtained earlier from HUS. In this e-mail message the researcher asked for the possibility to meet in person or at least visit the ward and leave information letter to the nurse's office. In the information letter was further information of the study and request to point out one or two parents who would potentially be interested in participating and able to do so. The researcher did not ask for the names or any other personal details of the parents or patients, only room and bed numbers.

The participants were chosen from amongst the parents or guardians whose child had been in the hospital overnight or longer. This method of sampling is called purposive sampling meaning that the participants are chosen from a certain group of people that are accessible for the researcher (Holloway & Wheeler 2013, 137-138). In this study the researcher approached parents whose child was admitted in the hospital at the time of the interview and who were present on the ward at the time.

The wards were given a date and a time when the interviewer come back to meet with the potential participants and ask for their consent in person. This however did not end up being very efficient method in recruiting participants as the researcher did not either receive an reply from the manager or the nurses did not have time to look for suitable candidates. In the end the researcher simply personally went to the wards, met with the manager if her or she was present and after obtaining consent from the manager, asked the ward staff to suggest some parents who may be willing and able to talk to me. The families were then approached in person and the researcher introduced the study and herself both verbally and on paper. The parents were given some time (up to 10 minutes) to think about participating and reading through the information letter (Appendix 2). If they consented, they were asked to sign the consent form (Appendix 3) and then were led to a suitable location for the interview. This was usually either an empty patient room, unoccupied office or in two cases in the parent's own child's room. On both cases the child was under the age of 2 and the parent was unwilling to leave the child for the duration of the interview.

The conducted interviews were recorded and then transcribed into text at the earliest opportunity immediately after the interview. The preliminary data analysis began after only two of the interviews were collected, by observing the themes and possible similarities between them. Written notes and reflective comments were also made after each interview to improve the ones in the future.

This is supported by Miles et al. (2014, 70). They state that analysis concurrent with data collection can help the researcher to better and correct them while the collection process is still going on.

5 Data analysis

The inductive content analysis was used when analysing the transcribed interviews. Hirsjärvi, Remes & Sajavaara (2013, 164) state in their book that inductive analysis is the method of choice in qualitative study, as the goal is to find something previously unseen, and the emerging themes cannot be predicted or decided upon before the analysis. The aim is to find recurrent phenomena from the stream of experiences (Miles et al. 2014, 238)

The data analysis was begun by transcribing the interviews to written form. The interviews were conducted in Finnish, taped and then be transcribed from tape recordings to texts. The method of “jotting” (Miles et al. 2014, 94) was utilised by continuously making notes to be used in the analysis process. Those notes consisted of comments, ideas, feelings and occurrences that the researcher wanted to capture for the future, either to improve the quality of the future interviews or to explore in the process of evaluating the research ethics of the study.

The transcribed interviews were then read through, first in a more cursory way and then in depth. The coding process was completed in two consecutive cycles. In the process of first cycle coding, where the data is read through and divided into clusters of similar attributes, after which those sequences that emerged from it were translated into English. Both In Vivo coding and process coding were used. In Vivo coding utilises the participants own language from the data records giving them a stronger voices. (Miles et. al. 2014, 74) Regularities and patterns were searched from the data and draw together groups of similar features. The In Vivo codes were marked with quotation marks to differentiate them from the codes generated by the researcher. (See Table 1.)

The process coding tries to find the observable action in the data, using the “ing-words” or gerunds. (Miles et al. 2014, 75). In this thesis it became apparent that sometimes the way the parent expressed certain matter was not suitable to be coded in vivo even if there was a clear theme emerging from the section of data. The “key words” from that piece of data were then picked and the process code concluded all the while endeavoring to preserve its original message.

The second cycle coding included finding pattern codes consisting mainly of categories or themes (Miles et al. 2014, 87). The approach in this study was inductive and the aim was to find categories around themes that rose organically from the data, not the ones constructed for the interviews or found from the initial literature search. While many of the themes emerging from the data were similar to those used structuring the interviews, the researcher used only the data that was not a result of unintentional prompting or leading. (Holloway & Wheeler 2013, 98).

ORIGINAL QUOTE	CODE	SUBCATEGORY	CATEGORY	THEME
<i>"I have not stayed the night, not even asked if it's possible...I suppose it is, there's the bed in the closet"</i>	"I have not stayed the night, not even asked if it's possible"	"I'm allowed to sleep right next to him" (Based on a different quote)	Participation	Being a parent of hospitalized child
<i>"Because I think that a five-moth-old wonders a little bit where his big brother is--"</i>	The other sibling missing the hospitalised child	N/A	Support of the family	In the hospital as a family
<i>"We are the kind of people who ask---if there's something on our minds"</i>	"We are the kind of people who ask---if there's something on our minds"	"If I have questions I ask" (Based on a different quote)	Communication	Perceptions of care quality
<i>"They trust the child's word when she goes to bathroom and they ask 'did you pee or poop' and they trust and don't say 'I'll come and look'</i>	"They trust the child's word"	N/A	Hospitalisation's impact on normal childhood	Child as a center of care

<p><i>“I don’t know if in this age [the child was a baby] there is any significance on who the child shares the room with”</i></p>	<p>Sharing a room not being an issue for the child</p>	<p>N/A</p>	<p>Physical features</p>	<p>Features impacting the care</p>
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Table 1. An excerpt of the data coding process showing a quote, category and a possible sub-category from each of the main themes.

Part of the process was also constantly going back and forth between the data and the research questions, omitting some that was not relevant to the latter or adding some that had been previously omitted. This was also where the limited experience of the researcher became apparent and in the first interviews in particular the drop rate, the amount of data that is of no use for the analysis, was relatively high (Holloway & Wheeler 2013, 89).

Elo Kääriäinen, Kanste, Pölkki, Utriainen and Kyngäs (2014, 5) point out that interpretation is something that is impossible to completely avoid when approaching the text and it is important to make sure that the researcher does not invent the interpretations. This was found particularly challenging, and the categorisations were constantly reflected against the original transcriptions. Commencing the analysis while still collecting the data proved to be an efficient way to ensure the accuracy and credibility of the findings.

Silverman (2005, 185) emphasises the importance of going into the data analysis without any prematurely constructed theories or speculations about the motives behind the participants. On the other hand, he strongly advises researcher to start the data analysis “from day one” (Silverman 2005, 150), to stay on top of it. There was an apparent benefit in immediately transcribing the interviews after recording them and then being able to pick some outstanding themes or codes right away while the interview situation was still fresh in mind.

6 Findings

From this study rose five distinctive themes, four of which were related to the first research question. Theme *being a parent of hospitalised child* focuses on parents’ experiences of *participation*, *position* as a parent and *coping*. *Perception of care quality* explores the parents’ experiences of *professionalism and expertise of the staff*, *reasoning behind decisions*, *perceived continuity* and about *communication*.

Child as center of care focuses on the parents' experiences of the child-centricity of the care with categories *Child's opinion having value*, *hospitalisation's impact on normal childhood* and *child being in the center of care*. In features promoting or hindering the care parents' views on *abstract and physical attributes* as well as *treatment, confidentiality and privacy*.

Some quotes from the interviews have been used to allow the voice of the participants to be heard. The original quote in Finnish is cited first, followed by its English translation written in italics.

THEMES

CATEGORIES

-Subcategories

BEING A PARENT OF HOSPITALISED CHILD

PARTICIPATION:

"I'm allowed to sleep right next to him"

POSITION:

-Being involved as a parent by staff

-Authority over the child's care

COPING:

-Feelings of parenthood

-Physical coping

IN THE HOSPITAL AS A FAMILY

SUPPORT OF THE FAMILY

SUPPORT FOR THE FAMILY WITH COPING

PERCEPTIONS OF CARE QUALITY

PROFESSIONALISM AND EXPERTISE OF THE STAFF

PERCEIVED CONTINUITY

COMMUNICATION

-"If I have questions I ask"

-"Not in those medical terms"

CHILD AS A CENTRE OF CARE

CHILD'S OPINION HAVING VALUE

HOSPITALISATION'S IMPACT ON NORMAL CHILDHOOD

CHILD BEING IN THE CENTRE OF CARE

FEATURES IMPACTING THE CARE

ABSTRACT FEATURES

PHYSICAL FEATURES

TREATMENT

CONFIDENTIALITY AND PRIVACY

Figure 1. Themes, categories and subcategories from the findings

6.1 Being a parent of hospitalised child

This category can be divided into three subcategories: *participation*, which focuses on the ways the parents described they were allowed and able to participate into the child's care during hospitalisation; *position* focusing on their perceived role as a parent and negative or positive position of authority over the care as well as decisions related to it and *coping* describing how parents expressed their feelings of parenthood and the overall coping during the time of the child's hospitalisation.

6.1.1 Participation

"I'm allowed to sleep right next to him"

As a general rule parents were usually allowed to stay overnight. However, in some cases they were not made aware of this fact:

"Ei olla öisin oltu, että ei olla oikeestaan ees kysely että voiko olla...kyl se vissiin ---on, on toi sänky tuolla kaapissa."

"*We have not stayed the night, not even asked if it's possible...I suppose [---] it is, there's the bed in the closet*"

It seemed that parents in this example would have been happy to stay with their child overnight too, but they did not see their position as parents to be allowing that.

For most parents the mere fact that they were allowed to stay was enough, and the basis of all participation. It also became apparent that the possibility to stay with the child was seen more as a privilege than an obvious right. There were parents who expressed willingness to fight for the be allowed to stay with the child and along with this notion came the fact that the wards had different rules concerning parental presence during the night and the reasoning behind the was not always made clear.

For some reason or another some parents were not allowed to stay or were persuaded by a member of staff to go home in order to be able to sleep. Although in majority of the cases the parent were allowed to stay, some chose to stay home due to their own resources:

"On tarjottu sitä mahdollisuutta jäädä, --- mut meil ei oo niinku oma jaksaminen siihen riittänyt---et sitä omaa jaksamistakin täytyy niinku kuunnella..."

"*We have been offered the possibility to stay---but our own coping has not allowed that---you have to listen to yourself too...*"

The same mother noted also that had the hospital facilities been more accommodating than having only a mattress on the floor in a shared room she would most likely have stayed.

This notion of unpractical and crowded facilities was shared by nearly all of the participants. It was not enough that the parents were given permission to stay when the facilities did not often support that. One father pointed out that reason he did not stay was because his child did not feel it was necessary. The possibility to stay the night seemed to be more significant for the parents of smaller children and also if the child was acutely ill.

6.1.2 Position

This section includes both the preservation and value of parental role in hospital as well as their position of authority versus that of health care professionals’.

Being involved as a parent by staff

Parents also described situations where they had been actively involved by the member of staff:

“Hoitaja sano, et tulkaa hänen kanssaan niinkun keittiöön, et ‘mennään laitetaan [lapselle] ruokaa---on tämmönen lista et mitä saa ottaa ja mitä ei”

“The nurse asked us to follow her to the kitchen and said ‘let’s go prepare the meal for [the child]---and here’s a list what she can and cannot have’.”

Some of the participants reckoned that the nursing staff would perhaps want or expect the parents to participate in the care, but were unsure as to how to do that without endangering the child’s safety or breaking the rules. They expressed the need for the professionals to show and articulate the ways the parents were expected or allowed to get involved. Parents also seemed to be aware of the situation at the ward and that the staff was often busy with other patients.

Parents did not in general seem to grasp their value as co-carers. They expressed “only being able to small things” and described their part being about holding the child’s hand or providing emotional support. These tasks were usually following the word “only”, indicating that this was not seen as something insignificant with little impact on the care as a whole.

Authority over the child’s care

It was not always clear to the parents who held the ultimate authority over the care of their child and while that was often due to perceived lack of sufficient medical knowledge, the parents also often volunteered the authority to the health care professionals.

Although in the everyday care situations parents appeared to be heard, they did not for the most part expect to be asked permission. It is also to be noted that in order for parents to claim their authority, they felt that they needed to be informed of the care. The findings also indicate that the parents were unsure what was their legal position of authority in the decision-making. Although many of the parents recognised their moral right to know, they still were often unwilling to challenge the care decisions.

Some parents were expressing that they felt disempowered because they did not feel that they could be a part of the decision-making process due to the lack of knowledge. For many parents the fact that, no matter their lack of medical knowhow, they were the experts of their child was very important and sometimes felt that this was not supported by the health care staff.

One mother described a situation where she had had to adhere to doctor's orders even though they did not seem reasonable and felt particularly bad for having to force her child to do so as well:

“Mulla on aina pistäny niin vihaksi tota, että on ollu pakko pakottaa lapsi, että ‘nyt lasket housut, koska lääkäri haluaa, nyt sinä teet’ ja sitten me otetaan aina yhteen tytön kanssa, koska se sitten sen vihan kääntää tietenkkin muhun, koska ei se nyt vieraalle ihmiselle---“

“I have always become so angry when I have had to force the child: ‘now lower the pants because the doctor wants you to’, and then we battle with the girl-- -because she turns her anger to me, because she can’t do that to a stranger---”

In general parents seemed reluctant to question the decisions made by health care professionals, and this mother also in the end gave up because she “didn’t want to fight it”, even though she felt the situation was handled wrong.

6.1.3 Coping

In this chapter coping is used as a word to describe the parents’ perceptions of the effects and challenges child’s illness brings upon them. This includes both physical and emotional effects of the hospitalisation on their feelings of parenthood as well as other areas of life.

Feelings of parenthood

In this study many participants expressed that they needed support from the health care professionals in order to cope and being able to support the child. They felt strong sense of duty towards their children, both the hospitalised one and the others at home. This was realized for example by taking a combative position against the possible threats to the bond between

the parent-child unit.

The parents also recognised when the professionals, while possibly temporarily separating this unit, acted on what was seen as the best interest of the family. Example of this was when a mother was asked to go home for the night to be able to sleep better and recuperate from the physically and emotionally taxing experience of bringing acutely ill child to a hospital.

Some parents felt that the initial admission had affected the whole hospital experience, especially if it had been sudden and unexpected, like having to call an ambulance or rush to the emergency room. This had been traumatic to some parents and they revisited the experience during the interviews as well, reflecting on their emotions of the moment.

One source of emotional distress was anticipating bad news. One mother verbalized her feelings of living in a constant state of fear, as she felt that they had only so far received bad news from the investigations and tests that had been done to her child. The experience of not knowing and living in uncertainty was seen as a stressor by many participants.

The participants had different ways of coping and described the many effects the child's illness had on their parenting and their feelings of it. It appeared that especially if the child was small and the hospitalisation unexpected or sudden, the effects on coping were greater.

The participants also expressed the need for peer support from other parents. The method for this was to have a physical space for spontaneous gathering of the parents or then have organised peer support meetings. There often were not social quarters for the parents, and as the families were advised to stay inside the patient's room due to hygiene protocols, there was virtually no contact with other parents unless their child was sharing a room with another.

Overall coping

One participant noted how own coping affects on the overall experience at the hospital:

“Oma jaksaminen vaikuttaa siihen miten asiat kokee---pienetkin asiat voi niinku kärjistyä.”

“Own coping affects to how you experience things---minor things can escalate.”

It seemed in this study that often parents noticed their own exhaustion belatedly and wished that health care staff would urge the parents more emphatically to take care of themselves. When caring and worrying over the sick child was at the forefront of the parent's mind, the nursing staff's sensitivity and intuition to the situation was seen as important. The parents

reported even “collapsing” after a particularly traumatic experience and indicated that this could have been avoided by regularly enquiring after mother’s wellbeing as well, both physical and emotional.

Staff’s thoughtfulness and empathy was seen as support for coping, and parents were happy to remember the moments where they had been taken care of by the health care professionals. Often the care offered by care provider was simply an accommodation or the change to eat at an affordable price, which were both seen as significant help in overall coping.

All in all, it would appear that the support parents needed, the timing and preferred way to be offered it varied greatly between individuals. There was no “one size fits all” solution as the families and their needs were also different.

The majority of the participants felt that while the attitudes of the staff may have been supporting, the physical environment was not.

“Oma jaksaminen ei vaan riitä siihen et nukkuu patjalla tossa noin niinku katkonaisesti pari-kolme tuntia ja valvoo päivät.”

“I just can’t cope when I have to sleep on the matrass on the floor on and off two to three hours, and staying up during the days.”

Some participants felt that the help was not enough just to have within the hospital, that the disruption of normal routines caused stress as well. While the priority was obviously the hospitalised child, other everyday routines and household tasks added to the stress level. Many of the participants’ extended family lived far away and were of no help in terms of housework or tasks at home. As the hospitalization, child’s illness and all disruption they causes could be seen in several areas of the family’s life, the help the parents hoped for was holistic and family-centric.

6.2 In the hospital as a family

During the interviews for this study it became apparent that family was as central an aspect of life for the parents as the child was, and they were often undistinguishable. The parents expressed worry for other members of the family and seemed to feel the disruption of life particularly in the effects it had on the family as a unit.

6.2.1 Support of the family

When asked about family-centred care, many of the participants in this study identified it as a model of care where the whole family is attended to as an extension to the child. They

mainly focused on the practical aspects such as facilities and the possibility of the whole family to be present at the hospital.

Child's age was a factor as well when parents considered the meaning of family-centred care. For the parents of small children and babies the bond between members of family appeared more prominent in the discussions.

“Ku kyl mä luulen, et viiskuinenkin vähän ihmettlee, et missä on se isovelji.”

“Because I think that a five-month-old wonders a little bit where his big brother is.”

Participants also pointed out the co-parent's value as an emotional support during the taxing time of child's illness. While usually only one of the parents were allowed to stay overnight in the hospital and able to participate full time, the other parent's presence and support was seen as very significant.

According to the participants the reason the care was not perceived to be family-centric was usually that the facilities did not make it possible. The rooms were either shared with other patient and his or her family or they were single rooms, which were seen as small and crowded. These matters alone made it virtually impossible for the whole family to be present and participate in the care at the hospital.

The majority of the participants expressed a wish that there would be a possibility for the whole families to stay together throughout the hospitalisation of the child.

“Jos siel ois semmoset perhehuoneet, et siel vois niinku koko perhe olla ja vanhemmat pystyis ---käydä töissä sieltä käsin---ja sisarukset vois olla siellä.”

“If there were such family rooms where the whole family could be and the--parent could go to work from there---and the siblings could be there.”

The fact that the family-centred care did not get realised in the hospital setting was rarely because the staff neglected to deliver care following this model, but more because the facilities and the health care system did not support it

The family-centred care often extended to the family members at home. The parents noted that the healthy sibling also needed their parent and they had to be creative in finding ways to spend time with them too.

“Me ollaan siel keskenämme siel huonees---toki ollaan sitten yritetty välil sitte isommallekin, et on jotain muuta ajateltavaa. Hän on joka päivä sit käynny toisen vanhemman kaa jossakin.”

“We have been on our own in the room---sure, we have tried to give the older one something else to think about. He has gone somewhere with the other parent everyday.”

The need to be together as a family appeared to be the most common feeling amongst the participants. Although able to take part in the immediate care of the child and even stay overnight next to him were considered important, many parents expressed that privacy as a family was lacking in a shared room. Mothers and fathers from different families may have been forced to sleep fairly close to each other with nothing separating one family from another.

6.2.2 Support for the family with coping

As pointed out by many participants, the physical facilities did not necessarily support the family-centred approach, but the health care staff still made a difference by being flexible with the visiting restrictions - or perhaps the restrictions should have been adjusted to fit the current situation at the ward environment.

“---Tos on ilmeisesti toi rajotus, et kaks henkilö kerralla, mut me ku nyt ollaan nelihenkinen perhe, ni me ollaan kyl saatu olla.”

“---There’s apparently a restriction that no more than two people at the time, but we are family of four, so we have been allowed here.”

One mother stated that even though the staff most likely had her best interest in mind separating her from her infant child she had not been able to understand that when this was happening. She had been asked to go home to rest instead of staying at the hospital with child the first night there. Retrospectively she considered this as an act of kindness, but still had mixed feeling about it.

It may be difficult for the health care staff to evaluate which option is better from the point of view of the family: to let the mother sleep at home and perhaps rest a little better or lessen mother’s anxiety and protect the child’s right for parent at the hospital by letting her stay. The bond between an infant child and its mother was seen as something not to be violated under any circumstances.

This comment was made by a mother who felt that instead of being treated as a family, only people being attended to were the ones in the hospital, while father and older sibling at home were not considered. This is overlapping with the category of *coping* under the theme of *Being a parent of hospitalised child*.

There was also a need for support from other families in a similar situation:

“Tää osastolla oleminen vanhempien kesken...vois olla jotain vertaistukikoontumisia esimerkiks, et ois joku tietty kellonaika, et vois käydä juttelemassa---“

“This being on the ward amongst parents...there could be like peer support meetings for example, that there would be a certain time of the day, that you could go and have a chat---“.

Many parents in this study brought forward a wish for family-accommodation at the ward, so that the whole family could spend time together and live as close to normal as usual. The disruptive effect of the child’s hospitalisation on the family life as whole was a reoccurring theme in nearly all of the interviews.

The need for family rooms was expressed mainly by parents with smaller children. It seemed that the more the child was age-wise and developmentally depended on his or her parent the more the need for the whole family present at the hospital was apparent. The parents of adolescent children tended to be more inclined to communicate with the rest of the family via Internet or telephone than the ones with younger children.

6.3 Perceptions of care quality

Parents perceptions of care quality included following subcategories: *professionalism and expertise of the staff, perceived continuity and communication*. When talking about the quality of care in general the parents perceived it to be very high, but when they went into details it was also clear that there were many things to improve, although it may not have had an effect on the overall experience.

6.3.1 Professionalism and expertise of the staff

Most of the participants of this study felt that the expertise and skillset of the health care professionals were sufficient and adequate. Most of the participants were quite willing to acknowledge that there were different levels of experience among the professionals, and appeared generally understanding if this was a cause of some confusion or mistakes.

The parents expressed that the skills of the members of staff and ability to interact professionally depended on the nurses’ experience and age.

“Tietysti mitä nuoremasta hoitajasta on kysymys, ni sitä enemmän se menee oman työn, et keskiös on se, mut mitä enemmän se on tehny ni sitä paremmin pystytään ottaan huomioon se lapsi siinä. Toisillahan se tulee enemmän luonnostaan kuin toisilla.”

“Of course, the younger the nurse the more in the center is her own work--- but the more she has experience the more she is able to pay attention to the child there. With other it comes more naturally than with others.”

Few of the participants also recalled situations where they as parents have been the ones to educate the health care professionals in the specifics of their child’s care. This again was not necessarily seen as a negative thing and one of the parents expressed a real willingness to be in the position of a teacher concerning the particulars of the child’s chronic illness.

Some parents were mistrustful of the health care professionals, especially doctors if they had had negative experiences previously. There were several occurrences where the parent was not believed or “taken seriously” by a professional, which in turn made the care seem neglectful.

When it came to necessity of care provided, parents were generally trusting that no unnecessary risk would be put upon the child, although they did not always feel sure why any particular test was seen as essential.

“Silleen niinku hirveen inhimillisiä niinku kuitenkin lapselle ne, et varmaan ei ylimääräisiä kertoja haluta nukuttaa...”

“It has been very humane for the child---they probably wouldn’t put them to sleep for more often than they have to...”

No participant of this study expressed unhappiness in having their child admitted to hospital - in fact some felt that it should have been done earlier. The initial admission was perceived to be traumatic or negative when it did not happen soon enough or when the parent felt they had had to fight for the child’s condition to be seen as what it was.

6.3.2 Perceived continuity

In this study parents viewed continuity mainly from the point of view of the nurse-patient and doctor-patient relationships. Having a named nurse was seen as a sign of continuity, although this was not perceived as the only aspect of it. Parents also observed that although the child may have had a nurse named for him or her, they still did rotate greatly.

“Lääkäri on yleensä ollut samat naamat, kyl noi hoitajat täs kiertää vähän huoneest toiseen.”

“The doctors are usually the same, the nurses rotate from room to room.”

While this may be due to the three-shifted nature of the nurses’ work schedule, it was also

apparent that naming a nurse to each child was not a fixed practice in every ward, from one reason or another. This was also noted by the participants. While the communication and information sharing between the members of staff was seen generally sufficient, the change in the care was seen as apparent when the person providing it changed.

In this thesis study parents were inclined to understand that the circumstances at the ward sometimes required nurses and doctors to rotate, as long as the care continuity remained and all members of staff followed the plan. The active and apparent consultation between different specialties and disciplines was seen as a sign of good continuity of care and supported the trust and faith the parent had for the professionals. At the same time, some of the participants of this study also felt that when the communication was lacking between professionals and facilities it also affected them.

6.3.3 Communication

The communication between the members of staff and the family was looked mainly from two perspectives: subcategory of *“If I have questions I ask”* describes parents’ experiences on staff’s availability for questions and *“Not in those medical terms”* how the questions were answered or information of the care was initiated to parents. It is also a subcategory for experiences where parents felt that decisions concerning the care had not been explained properly to them.

“If I have questions I ask”

The parents whose child had been hospitalised for the first time needed more in-depth information of their child’s illness and the general practices of care.

Parents in this study also reported on situations where the given information was confusing or inconsistent. Confusion often occurred when written information was contradicted by what was actually practiced by the staff.

“---ja sain sit sen käsityksen et ei o muuta vaihtoehtoa ja menin kotia ja luin sitä osastoesitettä ja siinä luki että vanhemmat saa yöpyä...ja olin vähän hämmästynyt, et miks mä en sit saanut--“

“---and I got the impression that I had no other option and went home and then I read the ward leaflet and it said there that the parents are allowed to stay---and I was a bit baffled as to why I wasn’t then--“

It is also worth noting that many parents in this study also felt that it was good if rules and practices were flexible, especially if it was due to the individual needs of the family. At the same time it became clear that the parents hoped for consistency and reliability of provided

information.

The majority of the participants had assumed a position that they were ready to initiate the sharing of information by asking the questions if needed. In some cases it was seen as the responsibility of the parent to be active in initiating the information sharing. Some of parents were under the assumption that it was entirely up to them to demand the information about the things they wanted to know in general and did not expect anything different while in the hospital.

At the same time though, for this to be a way to gain sufficient information about the child's care the parent needed to know what to ask. Parents whose child had been hospitalised previously because of their illness sometimes felt that not everything needed to be told as some things were self-explanatory.

In this study it was not apparent if parents were allowed generally to participate in doctor's rounds. However, seeing that parents expressed a strong wish to participate in the child's care as much as possible as well as being efficiently informed, it would probably be safe to assume that they would have appreciated the opportunity.

“Not in those medical terms”

The parents seemed to mostly trust that the care provided for their child was done with a specific reason, but were often unsure as to what that was. Sometimes even when there had been an explanation it had been given in such language that the parents could not understand it.

“---ois se kuitenkin kiva tietää, et mitä [kokeita] sieltä otetaan...tulis vaikka niinku paperilla et mitä on määrätty---et ei ois niillä lääketieteellisillä nimillä.”

“---but it would be nice to know what [tests] they are doing...like it could come on a paper what they have ordered---and not in those medical terms.”

Participants of this study did not generally expect to be asked permission for the aspect of the child's care, but many expressed unhappiness or uncertainty when the decisions guiding the care were not made clear to them. The treatment was seen as unreasonable or incomprehensible if the professionals failed to sufficiently enlighten the reasoning behind the decisions.

Judging from one mother's experience, even necessary and evidence-based procedure can be seen as intrusive and unnecessary if it not reasoned well enough to the parent as well as to the child. No matter how benign a motivation was behind this rectal examination performed to an adolescent girl, it was perceived by the mother and the child as extremely unjustified

and something that violated the child's dignity.

6.4 Child as a centre of care

No matter what the general model of care in the care facility was, for the parents the child was in the center of it. They were very observant in the ways the staff approached and they were prepared to forgo their own rights as long as the child was well taken care of and treated respectfully.

6.4.1 Child's opinion having value

In this study especially the parents of school-aged children felt that child's opinion needed to be taken into account and respected. Particularly in cases including invading child's privacy and threatening his or her dignity this right to self-determination was seen as important.

Particularly when it came to the parents of adolescents there was a great emphasis on the trust put upon them and the professionals working together with the family in supporting the child's own involvement to care.

“Luotetaan lapsen sanaan, et kun hän käy vessassa ja kysytään, et ‘tuliko pissa vai toimiko vatsa’, ni luotetaan, eikä sanota, että ‘minä tulen kyllä katsomaan’.”

“They trust the child's word when she goes to bathroom and they ask ‘did you have a pee or move your bowels’ and they trust and don't say ‘I'll come and look’.”

Trusting the child's word and showing respect toward him and her was seen as important for the parent as well. In some cases the child was even the one to initiate the changes in his or her care plan and it was seen as something to be facilitated by the care provider as well.

Also the parents of younger children appreciated the staff's effort to listen and follow the child's view and to support it as much as possible. Even a seemingly small thing such as talking the child through a particularly uncomfortable and frightening procedure was seen as significant gesture from the professionals.

In this study it did not become apparent why the child was sometimes not being informed or listened to, only that that was occasionally the case. Parents reckoned that there must have been a reason why the information was withheld or the opinion dismissed, but it did not make it acceptable in their eyes.

6.4.2 Hospitalisation's impact on normal childhood

For most parents in this study there were sufficient opportunities for play and recreation and simply pass the time for the hospitalised child.

“Onhan tuolla leffat ja kaikki ja pelejä on ja voisi pelaa tietokonepelejä jos haluis... ja on askartelutarvikkeita tuotiin heti huoneeseen---ja kirjasto käsi kysymässä, että saako olla kirjoja---.

“There's those movies and---games and one could play computer games if they wanted...and arts and crafts supplies were brought to the room---and the library came to ask if we wanted books---.”

Some parents expressed that there were more activities for small children than adolescents. Many of the wards were equipped to host children from various age groups, but not specifically for any of them. This often meant that the activities were lacking for very small and adolescent patients. The facilities were not in all wards suitable for a family with a newborn baby and were often downright hazardous in terms of playing and crawling for infants and toddlers.

Some of the parents of older children also expressed that their child had had the opportunity to go to school while in hospital. No matter if the child actually went to school during the hospitalisation, this was seen as appositive thing. Still, parents assumed different opinions on whether the child *had* to attend to classes - some saw it as a form of rehabilitation and care, some as too taxing a task for the child recuperating from an illness.

For the parents was important that the child was being able to be a child. The toys and decorations arranged specifically for their child was much appreciated and often seemingly as great source of joy as it was for the child.

6.4.3 Child being in the centre of care

The participants expressed being satisfied on occasions where their child was treated as a center of care as opposed of machines or procedures done to him or her.

“[Hoitaja] on muistanut ottaa sen lapsen huomioon---että vaikka [antaa] niitä lääkkeitä ja koneet piippaa, ni hän muistaa aina mainita---‘hei sinä oot siinä keskiössä’.”

“[The nurse] has remembered to pay attention to the child---even when [giving] those drugs and machines bleeping she always remembers to mention--- ‘you are in the center of this’.”

It was also seen as important that the child was treated with respect and care. Parents noticed personal differences in the staff’s ability to attend to the child. The younger members of staff were often seen as more concentrated on their tasks and less attentive towards the child and the more experienced professionals as more child-centric in their actions and way of working.

Parents also listed being gentle, thoughtful and respectful towards the child as characteristic of good care.

“Hetä huomattiin et nyt tää on kipee ja heti annettiin kipulääkettä---jokainen siirto mikä tehtiin, ni sanottiin, et ‘me otetaan nyt sinuu kädest kiinni, me tiedetään, et se sattuu, mut me tosi varovasti siirretään.”

“They noticed right away that the child is now in pain and gave pain medicine right away---every movement they made they told the child: ‘we’ll take your hand, we know that you are hurting but we are moving you really carefully.”

Expressions such as “right away” and “with timely fashion” show that when attending to the child, unexplained delays were seen as distressing and signs of indifference towards the child. While the parents were in their discourse understanding of the staffing situation and workload of the nurses, having to wait for help when anxious over the child’s state did not appear as justified for the parents.

6.5 Features impacting the care

This category consists of issues parents brought up when describing the hospital experience in general. *Abstract features* consists of non-tangible things such as emotions and experiences. *Physical features* are the ones that could be clearly defined and pinpointed either promoting or hindering the care. *Treatment, confidentiality and privacy* bring up ethical issues parents experienced during the hospitalisation.

6.5.1 Abstract features

Abstract, non-tangible centred on factors that had impact on the child’s, parent’s or whole family’s experience in the hospital.

“Ihan sama oikeestaan missä ollaan, et jos se hoito toimii.”

“It doesn’t matter where we are as long as the care works out.”

This quote reflects the general mindset of the participants. Although there were numerous issues with care, facilities and treatment that could be improved upon, according to parents good care - what ever that meant to each individual - was the most important attribute.

Although the ward allocation can be seen as a definitely physical feature of the care, parents often viewed the care environment as much wider or more abstract sense. Not all parents knew what the other options for placements were, so they were not able to compare. As there were several families from other hospital districts with previous hospital experiences the negatives and positives were often seen in relation to those other facilities.

Still, it was apparent that the most important factor in parent’s overall experience was their child’s condition and how it was treated. HUS was generally seen in favorable light in terms of care as whole and expertise of the professionals and lacking in physical facilities and condition of the Lastenkliniikka’s building.

The participants expressed in many ways being aware of the circumstances at the ward and seemed understanding of issues such as staff shortage, even if it had direct effect on their child’s care.

“Sillon ku me tultiin, ni sinä päivänä oli mikä henkilökuntapula ja kaaos, ihan sitä, et meidät jätettiin niinkun yksin pärjäämään---seuraavana päivänä se tilanne muuttu loppuu kohe, et voi olla et me vaan osuttiin niinku huonoon kohtaan.”

“The day we came here there was some staff shortage and chaos, we were left to fend ourselves---but the day after the situation got better towards the end, so maybe we just came at a bad time.”

6.5.2 Physical features

Physical factors with impact on care and overall experience of the participants were appropriateness of the facilities, comparisons to earlier hospital admissions and smaller but no less significant aspects which, while staying at the hospital, could become either promoting or hindering features.

The majority of parents had an opinion on sharing a room; mostly they wished that there would be single rooms, for various reasons. One parent, however brought up that there are occasions when sharing a room was even preferable.

“[Lasta] kiinnostaa lähinnä vaan muut lapset ja muut ihmiset---et se että on ollut huonekaveri on ollut tosi kiva.”

“*[My child] is interested mainly in other children and other people---so having a room mate has been really nice.*”

Although privacy was one of the most common arguments for single rooms, there were also other difficulties. Parents were sometimes unable to sleep when a patient sharing the same room was crying or being attended to by the staff or his or her parents. As seen in previous categories, the parental coping was greatly affected by their ability to rest and relax while in the hospital with the child.

The indoor air quality had become an issue for some participants that had been staying overnight with their child and this caused some worry over the child's also staff's health and well-being. Some experienced dryness of throat, running noses and eyes were reported by the participants. On the wish list of features in the new children's hospital went the safe and healthy structures as well as family-centredness and possibility for the parents to be more actively present in the hospital.

6.5.3 Treatment

The ethical themes rising from the data of this study were *treatment*, *confidentiality* and *privacy*. The issues concerning treatment were often related to the discretion and general behaviour of the health care professionals, but also situations where the parents felt that the professional did not attend to the child or the family's needs within a reasonable time.

“---Et sit ku tuol on niit kiireellisempiä, et [hoitajat] on ollu nyt aika paljon kiinni, et ku mä oon pyytäny apuu, et sit ei o ehditty tuolla---niin ihan kuin me ei oltais niin apua tarvitsevia.”

“---*Because there is so many more urgent ones, that [the nurses] have been quite occupied, so when I have asked for help there has not been time for it---as if we are not in need too.*”

Signs of good and respectful treatment were “being taken seriously” and staff attending to the child when parent felt it was necessary. One participant in particular reported of an inci-

dent where a member of nursing staff had refused to do a fairly basic care procedure with no explanation of why and without asking somebody else to do it instead. The parent was left with a feeling that the child was not seen as important as the rest of the patients at the ward.

Treatment was also perceived in the context of respectful and considerate behaviour of the staff. Introducing oneself was seen as important, particularly if the nurse was named for this family for the day. This was seen as adding to the trust and feeling of safety for the child.

One mother was particularly happy about the way her child had been treated while he was in pain. Tenderness and gentleness were seen as important especially when dealing with children and kind behavior as something that all members of staff were expected to show.

The general attitude of the professionals of the hospital were seen as good and fitting for the circumstances.

“Ollaan kuinka korkees viras tahansa, ni sellanen pönötys ainakin suhtees meihin on ollut niinku tipotiessään.”

“No matter how high an official you are, the sort of pompousness at least in relation to us has been non-existent.”

The lack of obvious hierarchy at least between the professionals and the parent was seen as commendable and in general the interaction with the child was perceived as natural and easy.

The instances where the behaviour was seen as inappropriate were when the staff was being inconsiderate of the circumstances. Comments that were most likely meant as jokes were seen as hurtful and offensive when the child's situation was dire. While not necessary meant as such this was still described thoughtless and out of place.

Parents were expressing being extra sensitive and emotional during their child's hospitalisation and needed staff to take that into account and be discreet.

“Mut yksiki hoitaja sano, et ‘koittakaa nyt elää täs mahollisimman tavallist elämää.’ Must se tuntu kamalan kurjalta---et eihän kukaan pysty silleen elämään ihan tavallista ja normaalia elämää [tässä tilanteessa].”

“One of the nurses said: ‘just try to live as normal life as possible’. That felt really bad---nobody can do that [in these circumstances]!”

While recognizing that this was mostly due to the overall emotional distress of the past days, one mother was still very upset over the comment, which she saw as degrading and dismissive.

It can perhaps be seen from the data under previous categories, that the needs of the families are many and the methods of coping vary from parent to parent. The heterogeneity of these experiences concerning treatment and emotional support expected from staff reflects on the multi-faceted reality of the health care professionals as well as the need professional, sensitive and empathic employees with highly ethical conduct.

6.5.4 Confidentiality and privacy

Parents expressed worry over the confidentiality of the information concerning their child's care. It wasn't so much due to the actions of the health care professional that it was about facilities and problems with them. Still, these problems were often enforced by lack of planning and consideration by the staff, particularly when the doctor or a nurse was discussing with or about the family by the child's bedside.

“---tässä kyllä sen lapsen tietosuoja täysin katoaa [kahden hengen huoneessa], kun se toinen äiti oli tässä ja kuuli kyllä kaikki mitä hoitajan kans puhutaan, ja kun lääkäri kävi, kuuli kaikki---hän pystys sitä tietoo niinku levittämään jos haluaisi.”

“---the confidentiality of information disappears completely here [in a shared room], when the other mother was here and definitely heard everything we talked about with the nurse, and when the doctor came she heard everything--and could spread that around if she wanted.”

The confidentiality became a concern mainly if the child had to share a room with another child. The parents did not spontaneously point out any particular actions the staff would have taken in preventing this. Oddly enough, while the other child's parents were asked to leave the room when the nurse came to educate the family, this was not mentioned anywhere else

Privacy issues were mostly due to the facilities. The lack of private space and “peace and quiet” was disrupting the recovery of the child and the family. The privacy was seen as an important value for both the child and the family as a unit.

“---Täs ei oo mitään verhoo, et ois niinku toimenpiteen ajaks---“

“---There's like no curtain here...like for during the procedures...”

Having a single room was seen as a way to protect the privacy of both the family and the child. Privacy was also mentioned as a significant factor in child's recovery and provider of safe haven from restlessness and noise.

In some occasions it was also a member of staff that was seen as invading the family's privacy. Barging into the room without knocking, dismissing the fact that the family may be still asleep and general tactlessness was seen as disrupting of privacy of the child and the family.

It is to be noted that the parents discussed matter of privacy exclusively from the point of view of the whole family - it appeared that child's privacy was seen as extension of the family's.

Parents also mentioned occasions where the privacy was made possible.

“[On ollut] silleen tarpeeks intimitettä, et nyt on isos huoneesa, ni tuotiin sermi väliin”

“*[There has been] enough intimacy and now in a big room they brought a screen between [the beds].*”

Not every parent expected to be placed in a single room and the participants seemed in general to be very understanding of the overall circumstances at the ward. The majority of the parents however seemed to be of the opinion that privacy and confidentiality would be best ensured in a single room.

7 Discussion

The research questions of this thesis were about the realisation of the rights of a hospitalised child, family-centeredness perceived by parents and ethical issues. It can perhaps be asked if any of those matters could or should be discussed as separate from each other as they all belong under the same umbrella - whether that umbrella was named “rights of the child”, “family-centeredness” or “ethical issues”. For the sake of convenience, however, those matters are discussed as their own initial themes, as much as they do overlap with each other.

7.1 Discussion of the findings

From this study rose five distinctive themes, four of which were related to the first research question. Theme *being a parent of hospitalised child* focuses on parents' experiences of *participation*, *position* as a parent and *coping*. *Perception of care quality* explores the parents' experiences of *professionalism and expertise of the staff*, *reasoning behind decisions*, *perceived continuity* and about *communication*. *Child as center of care* focuses on the parents' experiences of the child-centricity of the care with categories *Child's opinion having value*, *hospitalisation's impact on normal childhood* and *child being in the center of care*. In fea-

tures impacting the care explores parents' views on *abstract and physical attributes* as well as *treatment, confidentiality and privacy*.

Along with the EACH charter, as a frame of reference in this discussion is the original article by Migone et al. (2008): "Are we following the European charter? Children, parents and staff perceptions". In their paper the authors cast light on the quantitative questionnaire study done on Irish participants in the local hospital context. Although our health care systems and protocols are different, some of their findings support many found in this thesis study. As the aforementioned study does not include all the themes this thesis does, other literature has also been used to discuss the findings of this study.

Majority of European countries have agreed to follow EACH Charter, which defines the rights of the children while they are in the hospital. The charter includes ten articles with annotations and it is based on UN Declaration of the Rights of the Child (EACH 2006, 9).

How do the parents experience the actualisation of the rights of the child during hospitalisation in Helsinki University Hospital?

Although most of the participants in this study were allowed to stay in the hospital with their child, it was not always the case. In the EACH charter it is stated that the child should have their parent or parent substitute with them at all times during the hospitalisation. This includes at night, during resuscitation and during induction of anaesthesia, just to name a few. (EACH 2006, 12).

In some cases it appeared that the right of child for their parent in a hospital was not realised because the parents were not educated of such right. Some participants did not know that they were allowed or expected to stay with their child or they were led to understand that it was not preferable, for example because it may be difficult for parent to sleep in the hospital. Some parents also chose to go home for the night due to their own coping.

It may in some occasions fall on the health care professionals to make sure that the child's rights are realised by empowering parents to participate. On the other hand, as Vasli and Salsali pointed out in their article (2014) that if the parents do not know the meaning of their involvement in the care it is impossible for nurses to try to get them to participate. This could mean that if the parents are educated about the reasons their participation and presence is important they could very well improve those.

Meltzer, Davis and Mindell (2012, 67) studied the characteristics and quality of the parents' and children's sleep in the hospital setting, and found that it was significantly lower than at home. Parents reported sleeping approximately an hour less than at home and the sleep was much more fitful in hospital due to numerous disruptions and uncomfortable bed.

Against this backdrop it is perhaps understandable that, when added to the stress of having a sick child, these circumstances may prove too much to some parents and they choose to sleep at home in order to be able to participate at all.

Participation to care in general was seen often as a privilege given to parents by the hospital. Parents reported being “allowed to participate” and “only being able to help in small ways”, and on many occasions they seemed unclear as to what was expected of them in terms of involvement. Many were eager to participate and do as much as possible, but unsure as to what was safe and acceptable. They were often expecting guidance from the staff in caring for the child.

This was also found by Ahmann (2006, 88), who studied ways to support fathers’ involvement in their child’s health care and noted that most fathers were willing to be more involved than they were given possibility to.

Vasli and Salsali (2014) concluded in their study that effective communication between parents and nurses is essential for parental participation. This should include education on the child’s illness and discussions on the duties trusted to parents to minimise safety risks.

According to the findings of this study it can perhaps be beneficial for parents for the staff to empower the parents in understanding their value as caregivers and support system for the child during the hospitalisation. In article 5 of EACH Charter (EACH 2006, 18) it is stated that parents should be supported in being involved in the care and the decisions guiding it.

In study by Migone et al. (2008, 411) quarter of the participating parents would have liked to be more involved in their child’s care. This, however, required them to be adequately informed about the treatment, which was not always the case.

Perhaps because Finnish laws and regulations within health care context do not require care providers to ask legal consent from the parents it sometimes creates “power struggles” or at least situations where it is unclear whose word weighs the most when deciding on child’s care. The Act on the Status and Rights of the Patient, section 7, regulates that in the case of minor children, the care must be decided on “mutual understanding with his/her legal guardian or representative.” (FINLEX No. 785/1992).

In the study by Migone et al. (2008, 411) showed that the more previous admissions the child had had, the more adequately informed the parent felt. That would mean then that parents having their child hospitalized for the first time would need more in-depth information and education about their child’s illness and care. This was something that did come up in this study as well.

One way to improve communication between parents and health care professionals is to allow

the parents to be present during the daily doctor's round (Comp 2011, 242). In this study it did not become clear whether or not the parents were allowed to participate in the doctors rounds, but seeing that they in general were willing to participate as much as possible and needed all available information in order to be able to do that, it would be likely that they would have benefited from it.

Some participants in this study felt that while they were being informed and told about the details of the child's care, the staff tended to use incomprehensible language in doing that. "Hospital lingo" or medical terminology were something that most of the parents were not familiar with and by using it the staff lowered the quality of information they were giving.

The study by Migone (2008, 411) showed that while the majority of the health care staff felt that they used appropriate language when communicating medical issues to parents, a significant percentage of parents (43%) felt that they had not been told about the side effects of medications and treatments well enough. This can be perhaps due to the fact that it is sometimes hard for the health care professional to know the knowledge base the parent has about medicine and they also may forget that that the language they are using is only used amongst professionals.

All in all, it seems that parents didn't generally mind having to be the ones to initiate the communication. On the other hand, as the parents have the right to be informed about the care of their child in a timely fashion (EACH 2006), it can be asked whether it should be up to the parents' activeness how much they are involved by the staff.

In EACH charter (EACH 2006) it is clear that the child should be in the centre of his or her care and being included into decision-making as much as possible. In the study by Migone et al. (2008, 412) it was shown that majority of the children wanted to be told as much information as possible, particularly those with five or more previous admissions. The same article discussed the concept of competence, especially in giving consent independently. Although this is also dependent on the state's legislation, it is important to take into account child's developmental stage as well as his or her own preference.

As is the case with parents as well, in order to make informed decisions the child needs to be informed about his or her care. However, how much and what form of information is fitting is up to discussion. (Migone et al. 2008, 413-414). Migone et al. also pointed out that being informed makes the child gain sense of control over his or her care. Situations where the child was not properly informed where in their study usually due to lack of time.

In my study it did not become apparent why the child was sometimes not being informed or listened to, only that it did not always happen. From the parents and children's point of view

it perhaps does not even matter why it did not, as according to EACH charter (EACH 2006) they simply do have the right to be a part of the decision-making. The discussion of competence often takes place when the child's participation and informed consent comes up. While that is definitely one way to approach the issue, EACH Charter does not make distinction in that sense.

Care continuity and relationship continuity in care is often seen as essential part of quality of care, as it promotes the trust and is beneficial for both the patient and the care provider (Williams 2014, S22).

Parents seemed in many ways to be very aware and even considerate on the staffing situation at the ward. Although they acknowledged that the nurses did rotate greatly from day to day and that the doctors kept changing too, they also were happy with the perceived communication between the members of staff. As long as the care plan was followed and the lines of care did not change unexplainably, the parents were quite willing to be understanding of the situation.

Williams (2014, S22) states that care continuity can be seen both from relationship and management points of view, relationship continuity being reflected on above and management view being about the care continuing along similar lines despite of the persons delivering it. She concludes that the relationship continuity is the most important aspect of care continuity. It can perhaps be argued that relationship continuity does not necessarily have to mean having the same person to care for the child several consecutive shifts. Maybe the continuity can be preserved also when the health care professionals share the same attitude and care philosophy. This could be something to consider when the rotation off the nursing staff becomes more rule than an exception in all health care facilities.

The Article 9 of EACH Charter (EACH 2006, 24) states that the continuity of care should be ensured within the team looking after the child. Whether this means relationship continuity or continuity of plan is not clarified, and perhaps it is not even necessary. When the people caring for the child remain the same, it is very likely that the plan stays as well. The participants of this study felt that the turnover rate of the nursing staff in particular was sometimes high, but that the continuity was still mostly achieved,

Barling, Stevens and Davies (2014, 152) mentioned in their article that in a questionnaire done to a health provider showed that interpersonal care was considered as most important aspect of quality care. Other characteristics were unmet needs and physical aspects of the care facility. Unmet needs in this thesis were things like not being heard as a parent or feeling that the child was neglected while the staff was attending to other patients.

How do the parents experience the family-centred care during their child's hospitalisation?

Family is essential support for the child and acts as a "constant in the storm" for him or her during the trying time of illness and hospitalisation. It is central for the child's development and nurture. (McKay & Gregory 2011, 43).

The family-centred care was perceived by the participants of this study as a model of care that attends to the family as a unit. Although the staff's attitudes and general atmosphere was seen as fairly family-centric, the physical circumstances and facilities did not always support that. Nearly all of the participants wished that it would be possible for the whole family, or at least both of the parents to stay on the ward with the child, seeing that as the essence of family-centeredness. This was not however made possible for any of the participants, and although they understood it was more due to the physical restrictions than the willingness or attitude of the health care professionals, it was nevertheless seen as something to improve on.

The study by Migone et al. (2008, 413) also showed that the hospital facilities were not what they should have been in terms of supporting the parental presence and participation.

As became apparent in this study, the fact that the family-centred care does not get realised in the hospital setting is rarely because the staff neglects to deliver care following this model, but more because the facilities and the health care system do not support it. This was found also in the Irish study by Coyne et al (2013, 472). The participants of the survey identified the design of the health care system as the most influential in the fact that the family-centred care was not practiced in its entirety.

As family-centeredness is going to be one of the main values of the New Children's Hospital in Helsinki (Lahdenne 2013), it is then important to start building the foundation for it from the organisational level, not forgetting that although not the only factor, the facilities are significant in supporting true realisation of the family-centric care.

The study by Migone et al. (2008, 413) also showed that one third of the children were unable to spend as much time with their parents as they wanted. As discussed earlier, the fact that disruption to normal routines and family life is an added stressor in parents life, which in turn supports the notion that family-centred care is an approach that is emotionally beneficial for whole family and further to the child's recovery.

What may be problematic for the realisation of family-centred care is the fact that there is very little literature or guidelines for nursing staff on how to approach this model in practice. There are also numerous different definitions of family-centred care and that may cause even more confusion and misguided practices. (McKay & Gregory 2011, 44). Coping was mentioned by many participants as a factor most effecting their ability to participate in the care of their child. Coping was dependent of feelings that centered on the care, child and being a parent

and of matters that disrupting their normal routines as a family.

Salisbury, LaMontagne, Hepworth and Cohen (2007, 214) explain word *coping* as active methods parents use to manage emotionally stressful situations in their lives.

Study by Rempel et al. (2013, 622) showed that sometimes emotional coping was just “keep-ing on going”. This notion was repeated in this study as well by many participants. They ex-pressed that everything else in life became secondary while the child was hospitalised, in-cluding the parents’ own needs and wellbeing. It seemed that often parents noticed their own exhaustion belatedly and wished that health care staff would urge them more emphatically to take care of themselves.

Parental coping is an essential part of the care, as it has direct correlation with the child’s psychosocial well-being. Maternal worry and mental health had bigger correlation with child’s later behavioural issues than the reason they were initially admitted to hospital. (Rempel, Ravindran, Rogers & Magill-Evans 2013, 69). This promotes the idea that while attending to parents’ emotional needs one is ultimately looking after the child’s best interest.

Vermaes, Janssens, Bosman & Gerris (2005) write about parents’ psychological adjustment in the occurrence of a birth defect. They define it as the way of adapting to manage upsetting feelings caused by child’s illness as well as maintaining emotional balance. The authors point out that this adjustment process is individually characterised and the way parents’ cope with the child’s chronic illness is something that is dependent on how they appraise them. They also note that other changes in normal life routines and family life have affect on overall cop-ing.

The findings of this study showed that instead of psychosocial help being offered at the time of the initial crisis, it should be an on-going process, sensitive to parent’s individual situation. Parents felt that they were necessarily not ready to receive counseling when they were over-whelmed by their child’s illness and hospitalisation. Nevertheless they appreciated that the help was available when needed.

Lerret (2009, 247) found in their study on families’ discharge readiness that the amount of support the parent needs does not necessarily correlate with the severity of child’s illness. This supports the notion that all support and help strategies should be planned individually based on each family’s needs.

What other ethical issues do parents experience during their child’s hospitalisation?

The ethical concerns the participants brought forward were treatment, confidentiality and privacy. As this thesis was about family-centred care, the child’s and the family’s treatment, privacy and confidentiality issues are discussed as together.

The treatment of the child and the family was seen as adequate and appropriate in general, but due to differences in personalities of both the staff and the family members and misjudgment in some situations there was also some negative experiences. Parents perceived the treatment of the child as very good and respectful, but there were some occasions described when the child's voice was not heard or his or her right for self-determination and dignity was put under question.

This notion was shared with the study by Migone et al. (2008, 412), where overwhelming majority of the parents felt that their children were treated with understanding and sensitivity to the child's needs.

Article 10 of EACH Charter (EACH 2006, 25) states that the child should be treated tactfully and their privacy should always be respected. The Charter does not differentiate between children's age, developmental state or state of illness in terms of the rights.

The families were usually treated appropriately and their value to the child was understood. Nevertheless, the participants reported cases where a member of staff had acted in a hurtful manner and spoken tactlessly to parents who were going through a crisis. While the parents in this study expressed empathy and understanding over the health care professionals as persons, it was still seen as the staff's responsibility to be sensitive to the parents and children's emotional state. "Off-handed" or joking manner in communication was in some situations seen as inappropriate and insulting.

The privacy was seen as a problem mainly due to the physical circumstances at the wards. Parents brought up the fact that there was not always single rooms available, and if the family was actively involved in the care this was seen as a barrier for the privacy as a family. The participants expressed that staying in a single room with bathroom facilities the normal family life was not disrupted as much as it was when the room was shared with another family.

The article 10 of EACH Charter (EACH 2006, 25) also mentions the child's right to be alone when needed as well as spending time undisturbed with his or her family members. The vast majority of the participants expressed a wish that there would be "family-rooms", where both of the parents and other family members would fit nicely and all of them stay overnight as well.

Many of the participants in the study by Migone et al. (2008, 412) also thought that there was inadequate privacy on the wards. This perhaps goes to show that while Finland and Ireland are in many ways far from each other, the hospital environment does set some challenges for preserving the sense of normalcy and the child's right for personal space, which tends to diminish when admitted to hospital anyway.

Confidentiality was mostly seen as confidentiality of patient information. This was also something that was threatened by the physical restrictions. Parents were worried that while the child's matters were discussed by the bedside, the other child and family in the room would hear them and potentially be able to spread the information around. Even though the doctor's rounds were not necessarily done while the other family was in the room, the confidentiality was in jeopardy every time nurse or other member of staff came to attend to either child.

The Act on the Status and Rights of the Patient (Finland 1992) states that all information contained in patient records is confidential. While this information is not necessarily discussed with outsiders present, it may be difficult to completely avoid situations where some of the information bound in secrecy is heard by for example parent of another child. This can be particularly troublesome if the room is shared by several patients all of whom have family members present.

This is still the law, and the hospital environment should be planned and organised in such a way that these fundamental rights are realised. Whether this means building only single rooms or organising care differently is to be considered by decision-makers.

One distinctive theme that emerged from the data was the question of power and authority. From the discourse taking place during the interviews one gets the feeling that parents were often unsure as to who had the utmost authority in the matters of care concerning their child. There were even situations where the parent had expressed unwillingness or questioned the doctor's orders for investigation, but in the end gave up because he or she did not want to "fight" with the professionals, even if the child was resisting the procedure.

French philosopher Michael Foucault discussed the position of power in society, and the importance of knowledge and awareness in holding it (O'Sullivan Burchard 2005, 360). In nursing context it would appear that one who has knowledge also has the power. In this study the parents' were of the opinion that their permission or consent for the care was not necessary to be asked and in the end the health care professional's opinion won, whether they agreed with it or not.

As under aged child is under the guardianship of an adult it is an interesting dilemma: what power, if any, does the child have over his or her own care? As noted earlier in this report, children's consent may be sometimes asked, but if it is negative it is promptly dismissed by the adults. (Coyne & Harder 2011, 314). Even in the situations where the parents clearly felt that the child's right for self-determination was violated, they still felt compelled to follow the orders of the health care professionals.

These situations could perhaps be solved constructively by listening and then explaining to

the parent why the decision was what it was - as clearly they were not made in “mutual understanding” as the Finnish Act on Status and the Rights of a Patient would require (Finland 1992). It is also to be noted that, as Hallström and Helander (2004, 368) pointed out, it is the health care staff’s responsibility to support parents in advocating for the child’s self-determination in terms of consent to care.

Some participants also felt that their worry over the child’s condition or current situation was not always taken seriously or even listened to. It can perhaps be stated that because the parents know their children they then should be treated as the experts in interpreting their child’s needs and advocating their will.

In the Best Practice recommendation by Joanna Briggs Institute (Stephenson et al. 2012, s??) it is stated that by knowing their children and recognising his or her signs of pain parental participation is very important from the point of view of efficient pain management.

This also promotes the notion that parental participation is important particularly because they know their child the best and can act as interpreters between the child and the health care staff.

7.2 Ethical considerations

Prior to approaching the potential informants and commencing the interviews the researcher applied for and was granted a research permit from my working life partner Helsinki University Hospital District (HUS) by presenting them with this research proposal. In this proposal were included the thesis plan, the information sheet for the interviewees, the structure of the interview and the research permit form.

The founding principle in the preservation of the ethicality of this study was the protection of human rights. This is usually done by seeking an external review, from such bodies like research ethics boards. (Polit & Beck 2010,132). Although previously the researchers interested in interviewing or studying parents or families of the patients have been required to obtain a permission from ethical board of the hospital district as well, this was not the case anymore when I commenced the process of applying for research permit. This fact was confirmed by the secretary of the ethical board as well as the representative of working life partner.

The interviewees of any research are often chosen according to the purpose of it (Hirsjärvi & Hurme 2006, 83). In other words, they are a part of particular group, in this case parents of hospitalised children, in the summer and autumn of 2014.

To preserve the right of the participants, the research should, according to Tuomi and Sarajärvi (2013, 131) firstly explain the purpose and methods of the study to the participants as

well as disclosing the possible risks to their person. The potential participants of this thesis received a written information sheet (Appendix 2) explaining the purpose of it as well as the method, which in this case is interview. They were also offered further information of the study verbally prior to the interview and offer them the opportunity to contact the researcher after it, should any questions or concerns arise. Although, as Bourgeault et al. (2010, 595) point out, obtaining consent in this way may affect the way the participants choose to behave during the interviews, that is also the nature of the qualitative approach in general (Polit & Beck 2010, 260). The requirement for written consent is also stated in Helsinki University Hospital Research Guidelines (Lindfors, Ruuskanen & Haggren 2013).

The relationship between the informant and the researcher should be based on respect and equality in terms of human rights (Holloway & Wheeler 2013, 97).

Leino-Kilpi and Välimäki (2004, 290) also point out the importance of giving the participants opportunity to have information about the research process for the whole duration of it. The participants of this particular study were given the contact information of both the researcher and the tutor teacher.

The names of the participants or the their children were not asked, only the number of the room they were in. The researcher also did not ask for any information about the nature of the child's illness from the staff, but asked parents to tell something about the reason they had come to the hospital. All participants did choose to disclose detailed information about their child's medical condition, but to preserve the confidentiality and anonymity of the informants these are not revealed in this report. This protocol also supports the anonymous nature of the interview, as the interviewer is never disclosed the names of the interviewees. (Hirsjärvi & Hurme 2006, 83).

Secondly, as Polit & Beck (2010, 127) point out, the participants ought to give a voluntary consent and they should be able to refuse or discontinue their participation at anytime, as well as withdraw their part and data even after its collection. The participants should be made aware of what the research is about. HUS has it's own format for the information leaflet and this has been modified to fit the details of my thesis (Appendix 2). (Polit & Beck 2010, 127; Lindfors et al. 2013). This was given to the potential participants of the study prior to signing the consent form (Appendix 3), which came after the initial meeting with the interviewer and the chance to obtain more information from the study.

The participants should face no harm, physical or otherwise and their wellbeing should be the first priority of the researcher. (Tuomi & Sarajärvi 2013, 131). Should any participant have expressed any discomfort (for example emotional distress) or discontent, they would have been offered a chance to rethink their participation or continue the interview at another time. As the topic of this thesis may have proven to be emotionally taxing for some partici-

pants, the researcher reserved enough time for each interview as well as a location that allows privacy and peace. Some of the interviews were conducted at the patient's room if the participant was unwilling or unable to leave the child for the duration of it. In those cases the child was under the age of two and thus unlikely to be harmed despite being present during the interview.

The matter of confidentiality consists of the sharing the information collected during the interview process and using it only for the purpose previously agreed (Tuomi & Sarajärvi 2013, 131). Any personal information was not collected, such as names or contact details, from the participants and handled data with discretion and did not disclose any individual interviews to outsiders. Confidentiality and privacy were also considered when choosing the location for the interview. The possibility of an outsider overhearing the interviews was eliminated by carefully choosing the location. Present in the interview were only the researcher (A-S. Sorsa) and the interviewee and in some cases a small child (under the age of two) if the parent was unwilling to part from him or her for the duration of it.

7.3 Trustworthiness

Tuomi and Sarajärvi (2013,132) state that the reliability and ethics of the research are inherently bound together and there is not one without the other. According to them, the reliability of the study can be achieved only if the researcher follows the good scientific practice. That includes, among other things, ethically sustainable procedures and allowing complete transparency to the research process.

To ensure the trustworthiness of the data the researcher has to start by choosing the data collection method that best helps answering the research questions (Elo et al. 2014, 2). Conducting the interviews by using structures inspired by previously conducted study of similar characteristics (Migone et al. 2008) and assuming reflective attitude throughout the process, the researcher endeavored to answer the research questions.

In the interest of the validity, parents from several different paediatric wards were approached units to gain a wider understanding of the topic as a whole. Content validity is used to demonstrate how appropriate the instruments, such as the data collection and sampling, are in serving the purpose of the study (Polit & Beck 2010, 378). While Holloway and Wheeler (2013, 145-146) point out that larger sample size does not ensure the validity of the study, they also note that having too rich a data may prove it difficult to capture the true meaning behind the experiences of the participants. With the eight participants this research had the data turned out to be very rich with five emerging main themes and several categories and subcategories, providing complex and multi-layered findings.

Elo et al. (2014, 2) present in their literature review method of four characteristics to ensure

the trustworthiness of the research: credibility, dependability, conformability and transferability. These will be discussed in this chapter as a part of ethical consideration.

Credibility can be ensured by describing and identifying the participants accurately. (Elo et al. 2014, 2). In this study the researcher also had to preserve the rights of the participants, one of them being anonymity. That is why they are presented as a group with some general characteristics on the earlier chapters without bringing up any individual participants.

Dependability is, according to Elo et al. (2014, 2) a way of deciding how well the study and the data stays stable over time. As this thesis aimed to collect perceptions and experiences of its participants within their individual circumstances without any attempt to generalise it further, they will certainly stay as such for years to come.

According to Holloway and Wheeler (2013, 303) instead of generalisability, one of the approaches to trustworthiness of a qualitative study is transferability, which in essence means that the findings collected in one context can be relevant in similar situations or with similar sample of participants in different context.

Realisation of the child's rights could also be studied in the setting of education or any other hospital or health care provider or perhaps in the context of social services at the time of a crisis such as child's illness.

It is important to acknowledge that the researcher will always bring his or her own frame of mind to the interview and struggles with listening and observing the informant with as much objectivity as possible. (Tuomi & Sarajärvi 2013, 135-136).

Conformability is a way to describe the objectivity of the study. Confirmable research is one that succeeds in answering its original research questions and meeting its goal without it being the result of the researcher's bias or underlying assumptions. (Holloway & Wheeler 2013, 303). To avoid possible bias during the data collection and analysis the researcher excluded the parents of the patients on her own working place from the interviews. One also had to be particularly careful when translating sections of data from the interviews to English to preserve the original message and to not to alter the data. The researcher also took great lengths in trying to find the essence of what the interviewees were telling outside the theme given by the interviewer. This mainly included modifying the form in which the researcher was presenting each particular team of the interview to the interviewee to ensure it left enough room for them to express their views as organically as possible.

In nursing research the objectivity of the researcher and impartiality may become problems (Tuomi & Sarajärvi 2013, 136), especially in situations where nurses are researching the patients. This same argument may well be extended to the setting of this thesis, where a chil-

dren's nurse is interviewing the parents of the children in hospital. The researcher did introduce herself to the participants as a nurse but that at this very situation she was a student and a researcher and as such, "an outsider". The researcher also carried a staff identification badge, and the participants could see that she was employed by HUS. As such, one cannot ignore the fact that the participants were aware that they were talking to an employee of the hospital, and that this may have had an effect on their answers.

Transparency and openness are the keys to ensure that the research can be considered reliable and scientifically valid (Silverman 2005, 209). The researcher's aim was to be precise and consistent when analysing and reporting my findings. For research to gain trustworthiness the results have to also be reported honestly and without distortion. Plagiarism is considered to be a form of distortion and it refers to using previously done study or any text written by somebody else without referring to the original source. (Leino-Kilpi & Välimäki 2004, 292-293). The results of this study were reported as they were, and as complete unbiased is perhaps difficult to achieve in the situation where the researcher is part of the setting that is under scrutiny, the researcher have endeavored to be as open and transparent about the process and the references used.

Particularly from the viewpoint of credibility one has to be transparent and self-aware of herself as a researcher (Elo et al. 2014, 4). The researcher constantly reflected her process and made notes after each interview of how to improve.

Being a member of staff in Helsinki University Hospital, Women and Children's division, the researcher is bound to have some personal perceptions considering the topic of my research. The researcher did make an effort to look at the data as objectively as possible. As mentioned above, the transferability and conformability of this research will ultimately be determined based on the success in that.

As this was the researcher's first experience of qualitative research or interviewing, the quality of the interviews improved significantly towards the last ones. The researcher learned not to be leading with the questions and to avoid close-ended questions. Initially the researcher also had a tendency to stick to the predetermined structure rather than let the participant lead the discussion. This was also something the researcher was able to correct on the later interviews. The interview guide was revised during the data collection process to support the more participant-lead approach. While initial themes were not touched, the researcher found more efficient ways to approach them. For example, instead of asking how the participant experienced the family-centred care at the hospital, on the later interviews the researcher first inquired what the parent thought it meant as a concept and that naturally led them reflecting on how that was apparent in their experiences.

7.4 Future challenges

Children's rights in the context of EACH Charter are not still fully realised in the hospital setting. This is due to many factors, one of them being the physical facilities, which do not allow parents to fully participate in their child's care and the family to be attended to as a unit.

Parents could not always appreciate their own value as co-carers and were often unsure as to what was expected of them in terms of participations and decision-making. Parents also required the staff's support in taking care of themselves and in being empowered as carers.

The authority over the child's care and the decisions concerning it was a matter of concern as well. The balance of power particularly when an under-aged is the patient would be an important focus of research in the future. As the matter of competence is already widely discussed in literature and ultimate solution to that debate may be difficult to find, it would be useful to explore the views of the nurses, guardians and children of different ages on the balance of power. Questions like who holds the authority and when and who should hold it are going to be hard ones to answer. Whether it is to be viewed from legal or ethical standpoint is a matter of choice and interest when conducting a study exploring this in the future.

Matters of privacy and confidentiality are in the core of nursing ethics but they may still be missing on many occasions. When planning and designing new hospital buildings the values of the future hospital should perhaps be at the forefront of the minds throughout the process. While majority of the issues arose from the inadequate facilities rather than attitudes of the professionals, it is still a reflection of the organisational values and priorities.

It would also perhaps be beneficial to delve further into the matters of the preservation of the dignity and integrity of hospitalised child as well as the family. Researching the experiences of children, parents and the health care professionals would provide valuable information of the actualisation of children's rights in the wider sense too.

Seeing that there seems to be significant lack of knowledge about the rights of the child with both the families and the professionals, raising awareness of NOBAB standards and educating both the current and future health care professionals about both legal and moral aspects of the children's rights would be the first priority. While the general public may be aware of the concept of the rights, the particulars of it seem, at least based on the findings of this study, largely unclear.

It would be also beneficial to explore the realisation of the children's right or family-centred care within other cultural context as the ideas and concepts of family and its value in society differs greatly even within Nordic countries.

Although the quality of the immediate care provided was not under question on this thesis, all of the themes that emerged from the study are still inherently linked to it. As the New Children's Hospital in Helsinki aims to be "The best hospital in the world", this quality of overall experience needs to be considered from the moment the family steps in to the building.

In the future it would be enlightening to repeat this study with similar themes after the operations within the New Children's Hospital have properly commenced to see how well the founding principles are being actualised.

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Appendix 1

Themes for the interview

Background information of the interviewee:

- Position in the family (mother/father/guardian)
- Age of the interviewee
- Education -“-
- Occupation -“-
- Age of the hospitalised child
- Number of children at home
- Number of previous hospital admissions
- Reason for admission: planned, emergency or other?
- The quality of the child’s illness (acute, long term or recurring)
- How long has the child been in the hospital (during this admission)?

Themes for the interview with sample questions:

- **Necessity of hospitalisation; necessity of medical treatments and investigations**
(How did you experience the necessity of your child’s hospitalisation? How about the medical treatments and investigations your child has gone through so far?)
- **Staying at the hospital with the child**
 - **Accommodations**
 - **Arrangements for the rest of the family**
 (How have you been given the chance to stay with your child during the hospital stay? What arrangements has been made for you by the hospital staff, for example in terms of accommodation, to enable your stay with your child?)
- **Participation and decision-making in child’s care**
 - **Role of the health care staff**
 - **Information given by the staff**
 (In which way have you been given the chance to participate in you child’s care and decision-making? What was the role of nursing and medical staff in this? How do you experience the information given to you and your child by medical and nursing staff (quality and quantity)?)
- **Ward allocation and the expertise of the staff**
 - **Age-appropriateness**

- **Recognition of the developmental needs of the child**
 - **Education, play, recreational activities**

(How have the developmental needs of your child been taken care of by the hospital staff in terms of ward allocation and skills of the staff as well as opportunities for play and education and age-appropriate recreation?)
- **Continuity of care during the inpatient period**
 - **nurse-patient**
 - **doctor-patient**

(How has the continuity of care been actualised in terms of nurse-patient or doctor-patient allocation?)
- **Treatment of the child and family**
 - **Dignity, privacy, integrity**

(How have you experienced the treatment showed to you and your child by staff in terms of respect and understanding of privacy and dignity?)
- **Family-centred care in practice**

(How has the family-centred care actualised in practice? What kind of assistance or recognition as a family have you or would have required from the hospital staff?)
- **Ethical issues**

(What other, if any, ethical concerns have you experienced during your child's hospital stay?)
- **Ideas to improve the hospital experience for the whole family**

(Do you have any ideas or thoughts for the new children's hospital in Helsinki? What would in your opinion make the hospital experience the best possible?)

(Migone et al. 2008, 411-412; EACH 2006, 11-25)

Appendix 2

Information letter for the participants

Arvoisa vanhempi,

Lapsenne on hoidossa Helsingin ja Uudenmaan sairaanhoitopiirissä (HUS) Nais-
ten ja lastentautien tulosalueella. Hoitoon ja siihen liittyviin tehtäviin perustu-
en otamme Teihin yhteyttä tutkimustarkoituksessa.

HUS:ssa on annettu lupa suorittaa terveydenhuollon ylempiin englanninkielisiin
ammattiopintoihin kuuluva opinnäytteeksi tarkoitettu tutkimus: Rights of the
children in hospital care: parents perceptions (Suom. Sairaalassa olevien lasten
oikeudet: Vanhempien näkemykset). Tutkimuksen lopullinen raportointi tapah-
tuu englannin kielellä, mutta haastattelut suoritetaan suomeksi. Opinnäytetyön
tarkoituksena on selvittää, kuinka sairaalassa olevien lasten huoltajat kokevat
lasten oikeuksien toteutumisen hoidon aikana. Tutkimuksen suorittajana on sai-
raanhoitaja AMK Anna-Sisko Sorsa.

Kutsumme Teitä osallistumaan tähän tutkimukseen. Sen vuoksi kerromme seu-
raavassa tarkemmin, miten tutkimukseen voi osallistua.

Lapsenne osastolla työskentelevä hoitohenkilökunnan jäsen antaa teille tämän
kirjeen, koska arvelemme, että voisitte sopia tähän tutkimukseen. Mikäli olette
halukas osallistumaan, pyydämme teitä ilmaisemaan tämä edellä mainitulle
hoitohenkilökunnan jäsenelle. Tutkimuksen tekijä tulee tapaamaan teitä henki-
lökohtaisesti osastolle, jolloin saatte lisää tietoa tutkimukseen osallistumisesta
ja mahdollisuuden kysyä siihen liittyviä kysymyksiä.

Mikäli olette tässä vaiheessa vielä halukas osallistumaan, pyydämme teitä alle-
kirjoittamaan suostumuslomakkeen. Tutkimuksesta voi kuitenkin vetäytyä myös
suostumuksen antamisen jälkeen niin halutessaan.

Teidät kutsutaan henkilökohtaiseen haastatteluun Teille sopivana ajankohtana
ja Teille soveltuvassa paikassa. Haastattelussa on lisäksenne paikalla vain tut-
kimuksen tekijä. Haastattelu nauhoitetaan tulosten myöhemmän analysoinnin
mahdollistamiseksi. Kaikki Teiltä tutkimuksen aikana kerättävät tiedot käsitel-
lään luottamuksellisina ilman nimeänne tai muita tietoja henkilöllisyydestänne.
Yksittäisen haastattelun kesto on arviolta noin 30-60 minuuttia.

Tähän tutkimukseen osallistuminen on täysin vapaaehtoista. Osallistuminen tai
osallistumatta jättäminen ei vaikuta Teidän eikä lapsenne hoitoon HUS:ssa nyt
tai tulevaisuudessa.

Lisätietoja voitte saada seuraavilta henkilöiltä:

Anna-Sisko Sorsa (tutkimuksen tekijä) anna-sisko.sorsa@student.laurea.fi

Paula Lehto (opinnäytetyön ohjaaja) paula.lehto@laurea.fi

*{hoitavan lääkärin / tutkimusluvan myöntävän henkilön allekirjoitus ja päivä-
ys}*

Appendix 3

Consent form for the participants

SUOSTUMUSLOMAKE

Minä, _____, suostun osallistumaan haastattelututkimukseen, jonka sisällöstä minulle on tiedotettu edeltävästi sekä kirjallisessa että suullisessa muodossa.

Tutkimukseen osallistuminen on täysin vapaaehtoista, ja voin kieltäytyä siitä ilman perusteluja. Voin saada tietoa tutkimuksesta koska tahansa sen suorittajalta (yhteystiedot aiemmin annetussa kirjeessä).

Haastattelut toteutetaan nimettömänä, eikä minua tai perheenjäseniäni voi yksilöinä tai perheenä tunnistaa lopullisesta raportista. Haastattelut nauhoitetaan aineiston analyysia varten, mutta niihin ei liitetä mitään henkilökohtaisia tietoja. Haastattelunauhat säilytetään lukitussa tilassa tutkimuksen valmistumiseen asti, minkä jälkeen ne hävitetään.

Henkilötietojani tai perheenjäsenieni henkilötietoja ei kerätä eikä käsitellä tässä tutkimuksessa missään vaiheessa. Tutkimukseen osallistujista ei kerätä rekisteriä missään muodossa, ja kerätty haastattelumateriaali hävitetään tutkimuksen päätyttyä.

Antamiani tietoja käsitellään luottamuksellisesti ja vain haastattelijan itsensä toimesta.

Voin koska tahansa perua osallistumiseni ilman perusteluja, eikä siitä koidu seuraamuksia minulle tai perheelleni. Voin myös jo haastattelun annettuani pyytää ilman erillisiä perustelua tutkimuksen tekijää poistamaan antamani aineiston rekisteristään. Tästäkään ei minulle eikä perheelleni koidu seuraamuksia.

Paikka ja aika: _____

Allekirjoitus: _____

Appendix 4

Accompanying e-mail for the research permit application

Hei! Olen tekemässä Laurea-ammattikorkeakoulun englanninkieliseen YAMK-tutkintoon (Master of Health Care) liittyen opinnäytetyötä HUS-alueella. Aiheeni on "Sairaalahoidossa olevien lasten oikeudet - vanhempien kokemukset", ja olen haastattelemassa siihen Lastenklinikan ja Lastenlinnan potilaiden vanhempia. Tarkoitukseni on puolistrukturoidulla teemahaastattelulla kysellä vanhempien kokemuksia siitä, miten NOBAB-standardien mukaiset lapsen oikeudet heidän mielestään ovat hoitojaksolla toteutuneet. Haastattelut on tarkoitus toteuttaa täysin anonyymisti nimiä tai muita henkilötietoja kyselemättä. Myöskään potilasasiakirjoihin en koske.

Nyt kyselisinkin yhteyshenkilöni Susanna Ruuskasen kehotuksesta, onko tuollainen aihe edelleen sellainen, että siihen tarvitsee tutkimusluvan lisäksi eettisen lautakunnan puollon? Jos näin on, tutkimuslupa kuitenkin myönnetään vasta ilmeisesti puollon saannin jälkeen?

Kiitos etukäteen vastauksesta,

Anna-Sisko Sorsa
Sairaanhoitaja
LL11