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THE QUALITY OF PAEDIATRIC NURSING CARE – CHILDREN'S PERSPECTIVE

by

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To Sofia and Akseli

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ABSTRACT

The purpose of this three-phase study was to describe children's expectations and evaluations concerning the quality of paediatric nursing care and to develop a quality instrument for hospitalized school-age children. The aim of the study was to improve the quality of paediatric nursing in hospital.

In the first phase, data were collected through theme interviews and children's drawings from 20 preschool-age children (4 to 6 years) and 20 school-age children (7 to 11 years). The data were analysed by using content analysis. The children's expectations concerning the quality of nursing care were related to the nurse, nursing activities and environment; the physical environment was emphasized in drawings.

On the basis of the results of the first phase, as well as earlier literature and Leino-Kilpi's "Good Nursing Care" Scale, the instrument "Child Care Quality at Hospital" (CCQH) was developed and its psychometrics tested in the second phase. First, an expert panel (n=7) assessed the content of the instrument. Second, the instrument was pilot-tested twice by collecting data from hospitalized school-age children (n=41 and n=16); in the same step the content validity of the instrument was assessed by nurses (n=19) from five wards together and by children (n=8). Finally, the instrument was tested with hospitalized school-age children (n=388), and nurses (n=198) assessed the content validity of the instrument. During the development process of the instrument, the main quality categories - nurse characteristics, nursing activities, and nursing environment Cronbach's alpha values - improved. The principal component analysis supported the theoretical construct of the subcategories in nursing activities and environment.

In the third phase, data were collected with the CCQH III (version four) from the paediatric clinics of the five university hospitals in Finland from school-age children (n=388) aged 7 to 11. At the end of the instrument there were two sentence completions in which children were asked to describe their best and worst experiences during hospitalization. The data were analysed using statistical methods and content analysis. The children rated the physical nursing environment, nurses' humanity and trustworthiness, and caring and communication as excellent. They gave the lowest ratings to nurses' entertainment activities. The age of the child and type of admission were both related to the amount of information they received. Children's best experiences were related to people, their characteristics, activities, environment and outcomes. The worst experiences were related to being a patient, feelings related to symptoms of illness and separation, the physical care and treatment activities of nursing and to environment.

The study showed that children are capable of evaluating their care, and their perspectives should be seen as part of the entire quality development process to improve quality in practice with a more genuinely child-centred approach. The instrument CCQH is a potential tool for obtaining knowledge about children's evaluations of the quality of paediatric nursing care, but more testing should be done in the future.

Keywords: paediatric nursing, quality of nursing care, quality of health care, child, instrument

Tiina Pelander

LASTEN HOITOTYÖN LAATU – LASTEN NÄKÖKULMA

Hoitotieteen laitos, Lääketieteellinen tiedekunta, Turun yliopisto, Suomi

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TIIVISTELMÄ

Tämän kolmivaiheisen tutkimuksen tarkoituksena oli kuvailla lasten odotuksia ja arviointeja lasten hoitotyön laadusta sekä kehittää mittari kouluikäisille sairaalassa oleville lapsille laadun arviointiin. Perimmäisenä tavoitteena oli lasten hoitotyön laadun kehittäminen sairaalassa.

Ensimmäisessä vaiheessa 20 alle kouluikäistä (4-6v) sekä 20 kouluikäistä (7-11v) lasta kuvailivat odotuksiaan lasten hoitotyön laadusta. Aineisto kerättiin haastattelulla ja lasten piirustusten avulla, sekä analysoitiin sisällön analyysilla. Lasten odotukset lasten hoitotyön laadusta kohdistuivat hoitajaan, hoitotyön toimintoihin ja ympäristöön, fyysinen ympäristö korostui piirustuksissa.

Ensimmäisen vaiheen tulosten, aikaisemman kirjallisuuden sekä Leino-Kilven “HYVÄ HOITO” mittarin pohjalta kehitettiin “Lasten Hoidon Laatu Sairaalassa” (LHLS) mittari ja testattiin sen psykometrisiä ominaisuuksia tutkimuksen toisessa vaiheessa. Mittaria kehitettiin ja testattiin kolmen vaiheen kautta. Aluksi asiantuntijapaneeli (n=7) arvioi mittarin sisältöä. Seuraavaksi mittari esitestattiin kahdesti kouluikäisillä sairaalassa olevilla lapsilla (n=41 ja n=16), samassa vaiheessa myös viiden lastenosaston hoitajat (n=19) yhdessä arvioivat mittarin sisältöä sekä 8 lasta. Lopuksi mittaria testattiin kouluikäisillä lapsilla (n=388) sairaalassa sekä hoitajat (n=198) arvioivat mittarin sisällön validiteettia. Mittarin kehittämisen aikana päälaatuluokkien: hoitajan ominaisuudet, hoitotyön toiminnot ja hoitotyön ympäristö Cronbachin alfa kertoimet paranivat. Pääkomponentti analyysi tuki mittarin hoitotyön toimintojen ja ympäristön alaluokkien teoreettista rakennetta.

Kolmannessa vaiheessa “Lasten Hoidon Laatu Sairaalassa” (LHLS III, versio neljä) mittarilla kerättiin aineisto Suomen yliopistosairaaloiden lastenosastoilta kouluikäisiltä 7-11 -vuotiailta lapsilta (n=388). Mittarin lopussa lapsia pyydettiin lisäksi kuvailemaan kivointa ja ikävintä kokemustaan sairaalahoidon aikana lauseen täydennystehtävänä. Aineisto analysoitiin tilastollisesti sekä sisällön analyysilla. Lapset arvioivat fyysisen hoitoympäristön, hoitajien inhimillisyyden ja luotettavuuden sekä huolenpidon ja vuorovaikutustoiminnot kiitettäviksi. Lapset arvioivat hoitajien viihdyttämistoiminnot kaikkein alhaisimmiksi. Lapsen ikä ja sairaalantulotapa olivat yhteydessä lasten saamaan tiedon määrään. Lasten kivoimmat kokemukset liittyivät ihmisiin ja heidän ominaisuuksiinsa, toimintoihin, ympäristöön sekä lopputuloksiin. Ikävimmät kokemukset liittyivät potilaana oloon, tuntemuksiin sairauden oireista sekä erossaoloon, hoitotyön fyysisiin toimintoihin sekä ympäristöön.

Tutkimuksen tulokset osoittavat lasten olevan kykeneviä arvioimaan omaa hoitoaan ja heidän näkökulmansa tulisi nähdä osana koko laadun kehittämisprosessia parannettaessa laatua käytännössä todella lapsilähtöisemmällä lähestymistavalla. “Lasten Hoidon Laatu Sairaalassa” (LHLS) mittari on mahdollinen väline saada tietoa lasten arvioinneista lasten hoitotyön laadusta, mutta mittarin testaamista tulisi jatkaa tulevaisuudessa.

Asiasanat: lasten hoitotyö, hoitotyön laatu, terveydenhuollon laatu, lapsi, mittari

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ABBREVIATIONS

APSI	Adapted Patient Satisfaction Instrument
CCQH	Child Care Quality at Hospital
CCS	Clinical Consumer Survey
CSD	Children’s Social Desirablility Questionnaire
CSQ	Child Satisfaction Questionnaire
CSQ	Client Satisfaction Questionnaire
FCCS	Family-Centered Questionnaire
GNC	Good Nursing Care
GYV	Give Youth a Voice Survey
HCS	Humane Caring Scale
HRQL	Health Related Quality of Life
IDDM	Insulin-dependent diabetes mellitus
LHLS	Lasten Hoidon Laatu Sairaalassa
LOPPS	LaMonica-Oberst Patient Satisfaction Scale
MACS	Metro Assessment of Child Satisfaction
MPOC	Measure of Processes of Care
PAC	Physician Attribute Checklist
PALS	Patient Advice and Liaison Service
Par.SS	Pediatric Hematology/Oncology Parent Satisfaction Survey
PFSQ	Pediatric Family Satisfaction Questionnaire
PICU	Peadiatric Intensive Care Unit
PIS	Pediatric Inpatient Survey
PSQ	Pediatric Satisfaction Questionnaire
PSI	Patient Satisfaction Instrument
PSNCC	Patient Satisfaction with Nursing Care Checklist
PSS	Patient Satisfaction Scale
QUALPACS	Quality Patient Care Scale
SCC	Satisfaction Children Care

LIST OF ORIGINAL PUBLICATIONS

This academic dissertation is based on the following publications, which are referred to in the text by their Roman numerals from I to V:

I Pelander T. & Leino-Kilpi H. 2004. Quality in Pediatric Nursing Care: Children's Expectations. Issues in Comprehensive Pediatric Nursing 27(3), 139-151.

II Pelander T., Lehtonen K. & Leino-Kilpi H. 2007. Children in the Hospital: Elements of Quality in Drawings. Journal of Pediatric Nursing 22(4), 333-341.

III Pelander T., Leino-Kilpi H. & Katajisto J. 2007. The Quality of Pediatric Nursing Care in Finland: Children's Perspective. Journal of Nursing Care Quality 22(2), 185-194.

IV Pelander T. & Leino-Kilpi H. Children's Best and Worst Experiences during Hospitalisation. (resubmitted)

V Pelander T., Leino-Kilpi H. & Katajisto J. The quality of paediatric nursing care: developing the Child Care Quality at Hospital instrument for children. (Accepted for publication 9/2008)

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Summary also includes previously unpublished material.

1 INTRODUCTION

There were 894,590 children under 14 years of age in the Finnish population in 2007 (Tilastokeskus 2008). Children and their families are one of the main groups among the users of health care services. They use particularly primary health care and maternity services during their first years: they made 1,240,475 visits to child welfare clinics and 1,582,420 visits to school health services in 2006 (Stakes 2007a, 2007b). During their first years of life, children also frequently use health centre services - about 3.8 million visits in 2005 - and visit private health care organizations, totalling about 1.4 million visits in 2005 (Tilastokeskus 2007). Although the number of treatment periods decreased in paediatric special care in 2007, the consumption of hospital services is growing due to mental health problems and accidents (Tilastokeskus 2007, Stakes 2008).

During the past decade, there has been a growing recognition of the importance of children's rights and the need to listen to and consult with children both at an international and national level (United Nations 1989, Decree on Enforcement of the Convention on the Rights of the Child 1130/1991, Council of Europe 1996, 1997, Act 785/1992, Department of Health 2003, Act 1221/2004, Betz 2005, Act 72/2006, Act 417/2007). Article 12 of the United Nations Convention on the Rights of the Child (1989) states that children not only have the right to opinions of their own regarding the issues affecting them, but they also have the right to voice these opinions. In Finland, there are acts which clearly outline that children should be seen as active partners and allowed to influence matters pertaining to them (Act 731/1999, Act 1221/2004, Act 72/2006, Act 417/2007). In summer 2008, the Ministry of Social Affairs and Health (STM 2008a) published a report which emphasizes children's rights to participate. The European Association for children in Hospital (EACH 1988) has formulated children's rights in hospital, and emphasizes a child's right to information and participation in accordance with age and maturity, also stated in the Act (785/1992) on the Status and Rights of Patients. Today, it is increasingly accepted that children have the right to have their views taken into consideration by health care providers (Coyne 1998, Beidler & Dickey 2001, Curtis 2004, Hallström & Elander 2004, Coyne 2006a).

In this study, children in nursing and especially the quality of paediatric care in hospital are under investigation. Quality of care is a complex, multidimensional concept and can be defined and evaluated from several different perspectives: the organizational and the professional perspective, and that of the patient (Bond & Thomas 1992, Laschinger et al. 2005, Lynn et al. 2007). Since the 1990s, the patient's perspective has played an increasing role in the definitions and evaluations, and it has an essential role on both national and international level (Leino-Kilpi et al. 1994, Thomas & Bond 1996, Merkouris et al. 1999, Cleary 2003, STM 2001, STM 2003, STM 2008b). Quality of care is difficult to measure (Vuori 1987, 1991a, Merkouris et al. 1999, Johansson et al. 2002, Laschinger et al. 2005) although various instruments have been developed (e.g. Bond & Thomas 1992, Leino-Kilpi et al. 1994, Larrabee & Bolden 2001, Laschinger et al. 2005). The quality of paediatric care has usually been evaluated from the perspective of parents rather than that of the children themselves (e.g. Marino & Marino 2000, Moumtzoglou et al. 2000, Filani 2001, Shields & King 2001, Ygge & Arnetz 2001, Co et al. 2003, Stratton 2004, Ygge & Arnetz 2004, Ammentorp et al. 2005, Miceli & Clark 2005, Ammentorp et al. 2006, Lawoko 2007). This is the case, although Lebow (1974) recommended as early as three decades ago that both children's and parents' reactions to paediatric care should be investigated. In this study, the term "quality of care" is the broad expression for all fields in care. Under that, "quality of paediatric care" concentrates on all areas of paediatric care. Consistently, "quality of paediatric nursing care" focuses especially on factors related to nursing.

The scarcity of studies made from children's own perspective may be due to ethical (Coyne 1998, Lindeke et al. 2000, Murray 2000, Beidler & Dickey 2001, Lowden 2002, Rossi et al. 2003, Alderson 2004) and/or methodological dilemmas (Coyne 1998, Beidler & Dickey 2001, Rebok et al. 2001, Scott 2001, Lowden 2002, de Leeuw 2004) in conducting research with children. Parents and carers are typically consulted and seen as proxies of children's experiences, based on developmental psychology which sees the child as passive (Darbyshire 1993, Carter 1998, Hart & Chesson 1998, Kiernan et al. 2005). Parents have a pivotal role in paediatric nursing care and they have been seen as experts on their child's emotional and psychological care. Besides, they have an important role in consulting their children's experiences, especially with the youngest ones. (Darbyshire 1993, Evans 1994, Coyne 1996, Hallström et al. 2002a, Power & Franck 2008.) However, the extent to which parents are able to appropriately represent their child's experiences may be limited (Carter 1998, Hart & Chesson 1998, Miller 2000), so the best method for understanding children's experiences is to ask them. In addition, research (e.g. Alderson 2001, Hallström & Elander 2004, Forsner et al. 2005, Kiernan et al. 2005, Coyne 2006a) has shown that children are capable of expressing their views and opinions on a wide range of topics. The challenge is to identify methods which are sensitive and appropriate to a child's age. Seeking and studying children's views along with those of parents and carers is important not only for the individual child or for his or her family, but also for the future of developing nursing care.

In this study, the interest lies in the quality of paediatric nursing care from children's perspective. The focus of the study is on the quality of hospitals; this was selected because generally hospitalization is a stressful experience, even for children of school age (Bossert 1994, Forsner et al. 2005, Coyne 2006b). Children's reactions are influenced by their illness and getting ill, their growth and development stage and previous experiences about hospitalization. The younger the children the more dependent they are on their parents, so that they are not necessarily able to express their own experiences. (Erikson 1982, Callery & Luker 1996, Nurmi et al. 2006). Concentrating especially on children of school age was selected because of their greater cognitive, linguistic, social, moral, and emotional maturity. Children have a possibility to adapt to different situations and at this age their language skills expand, they acquire reading skills and they start to distinguish different points of view. (Piaget 1952, Selman 1980, Erikson 1982, de Leeuw et al.

2004, Kellet & Ding 2004, Nurmi et al. 2006.) School-age children experience getting ill and illness as a stress, risk for self-respect and self-image (Bossert 1994, Kyngäs 1995, Pölkki 2002, Coyne 2006a). Social relationships outside the home are also included in the growth and development stage of school-age children, together with a basic sense of security and emotional relationships provided by parents (e.g. Coyne 1996, Nurmi et al. 2006). Parents' role is important, but the child as a unique and autonomous person has to be taken into account in nursing. It is important to hear children's expectations and evaluations of the quality of their care during hospitalization, since they are the main focus of care whilst hospitalized.

The research process was divided into three phases. In the first phase, the purpose was to describe children's expectations about the quality of paediatric nursing care. In the second phase, the purpose was to develop an instrument for evaluating the quality of paediatric nursing care from children's perspective based on their expectations. In the third phase, the purpose was to evaluate the quality of paediatric nursing care as perceived by children aged 7-11 in Finland. The aim of the study is to improve the quality of paediatric nursing. The study also produces knowledge for clinical practice, nursing and health care management, nursing education and nursing science.

2 LITERATURE REVIEW

This literature review consists of three main parts. First, the quality of care is described, starting with quality as a concept, followed by definitions of quality of care and its assessments, especially from the patient's perspective. The literature review continues by looking at the quality of paediatric care, first from the perspective of the child as evaluator of the care or children together with parents, followed by an investigation of parents' perspective. Research concerning the perspective of parents is included in the review, despite the fact that children's perspective was the main focus of interest in the present study. Studies on parents' perspective provide information about the evaluation of the quality of care by parents and quality indicators used in paediatric care in parental evaluations; quite obviously, some quality indicators are the same from children's and parents' perspective. Another reason why studies on parents' perspective have been taken into account is that there are only a few studies from children's perspective, and parents have a pivotal role in paediatric care, where parents' participation in caring for hospitalized children is the cornerstone of modern paediatric nursing. Finally, the quality instruments used in paediatric care are presented and analysed. The literature review focuses particularly on hospital settings and on studies concerning somatic care. In the review, the concept of quality of paediatric care is used, because in many evaluations of the quality in paediatric care, the quality of nursing care is only part of a more extensive area of evaluation. The concept of paediatric care thus gives a more detailed view about the phenomenon. The empirical part of this study focuses especially on the evaluation of the quality of care in paediatric nursing, and the concept quality of paediatric nursing care is used in this connection.

2.1 The quality of care and its evaluation

There is a lot of research on the quality of care. In this study, dictionary definitions and general articles concerning especially hospital and somatic care on the concept of quality were used in defining the concept of quality. Articles and empirical studies from 1989-2008 (Table 1) related to quality were searched from the Medline and Cinahl databases. In addition, sources were searched from those among listed in article reference lists. The main emphasis was on articles dealing with the patient's point of view. At this stage, studies on paediatric nursing were not looked for, because the aim was to examine the concept of quality on a general level. Studies in the area of paediatric nursing are looked at in more detail in 2.2.

2.1.1 Quality of care

The word "Qulais" is Latin and means "what kind of" (Nykysuomen sanakirja 1996). In Finnish, the word "laatu" (Finnish for "quality") comes from the Russian word "lad" meaning peace, harmony, joint, seam and order (Meri 1985) and it is known in Finnish literature since the 1680s (Nykysuomen sanakirja 1996).

Definitions in English dictionaries indicate that "quality" is any of the features that make something what it is. Someone's quality is the good characteristics that they have which are parts of their nature; they describe a particular characteristic of a person or thing. Quality is also a high standard of something, and it is used to describe how good or bad is it in relation to other similar things. Quality often seems to relate to something good or excellent, such as degree of excellence, good moral or superiority. (Collins Cobuild English Dictionary for Advanced Learners 2000, MOT Collins English Dictionary 2.0 2000, Oxford English Dictionary 2008.)

Finnish dictionaries indicate that the word "laatu" is the set of features that make something what is it ("mikä on jllek ominaista, jnk ominaisuudet"); quality is what is characteristic of something ("luonne, olemus, kvaliteetti"). Quality is also used to imply type ("laji"), class ("luokka") or category ("kategoria"), and a mathematical unit ("matemaattinen mittayksikkö"). It also has the meaning "convenient" or "possible" ("käydä laatuun"). (Suomenkielen perussanakirja 1992, Nykysuomen sanakirja 1996, Kielitoimiston sanakirja 2006.)

The definitions given for the word "quality" in English dictionaries would seem to be in line with those presented in Finnish dictionaries. The concept of quality is very abstract in nature. Thus, in conducting research with children, it needs more concrete expressions. In this study the concept "good" and "ideal" are used instead of quality because it was thought it would be easier for the children to grasp. "Ideal" (ihanteellinen, ihanne-") is a principle, idea or standard that seems very good and worth trying to achieve, and it often refers to a person or thing that seems to be the best possible or perfect person or thing for it. An ideal society or world is also the best one can imagine. (Collins Cobuild English Dictionary for Advanced Learners 2000, MOT Collins English Dictionary 2.0 2000, Oxford English Dictionary 2008.) In this study, in Paper II the Finnish word "toivesairaala" was used. "Good" ("hyvä, laadukas, korkeatasoinen, hyvä, mukava, miellyttävä, hyvä, hyveellinen, kiltti, ystävällinen") means high quality, standard or level, as well as someone's behaviour and characteristics or attributes, positive qualities. "Good" also implies something that is desirable, acceptable or right. (Collins Cobuild English Dictionary for Advanced Learners 2000, MOT Collins English Dictionary 2.0 2000, Oxford English Dictionary 2008.)

The dictionary definitions indicate the abstract level of the concept; there is no unambiguous definition for the word in nursing science, either. Quality of care is a complex and multifaceted concept that is extremely difficult for researchers to measure (Donabedian 1980, Smith 1987, Attree 1993, 2001, Gunther & Alligood 2002, Currie et al. 2005). According to Attree's (1993) analysis, the concept quality is used to indicate excellence, ideal, fitness for purpose and conformance to standards, meeting the customer's requirements, satisfying needs and customer value.

There are many reasons for the difficulty of defining the concept of quality. According to Frost (1992) the concept could be modified in different contexts, it is based on the values and experiences of a certain community or society and it is bound to time. It can be determined as bad, good, minimum or maximum. In addition, definition of the concept is affected by economical, legislation and professional factors (Chance 1997, Aiken 2002, Tervo-Heikkinen et al. 2008) as well as individual values, beliefs and attitudes (Koch 1992).

The quality of care has different meanings for different people (e.g. Frost 1992, Larrabee & Bolden 2001). It can be defined by patients, nursing staff, organization or society (Laschinger et al. 2005, Lynn et al. 2007). Nurses' and/or doctors', leaders' of hospitals and patients' perceptions of the quality of care are rarely evaluated in same study or with the same instrument (Attree 2001, Shannon et al. 2002). While there are studies reporting congruence in the way nurses and patients perceive quality on a general level, a more detailed study reveals differences (Attree 2001, Idvall et al. 2002, Leinonen 2002, Shannon et al. 2002, Currie et al. 2005, Kvist et al. 2006). Attree (2001) reported that patients identified different levels of quality that depend on contextual and intervening conditions linked to environment, organization and the personal characteristics of both staff and patients. Staff often evaluates the quality of care in a more critical manner than patients (e.g. Leinonen 2002, Shannon et al. 2002). On the other hand, nurses have evaluated the quality more highly than patients (Idvall et al. 2002). Doctors have also evaluated the quality as being better compared to patients or nurses (Shannon et al. 2002, Kvist et al. 2006). Organization management emphasizes quality-related standards, the impact of work and patient satisfaction (Kvist et al. 2006).

From the point of view of society, quality has in Finland been defined as the ability to satisfy clients' need of services professionally, at a low cost and in accordance with laws, decrees and regulations (Idänpään-Heikkilä et al. 2000). The National Research and Development Centre for Welfare and Health (Stakes 1996) published national quality-management guidelines in 1996. The guidelines were updated at the end of the 1990s (STM et al. 1999). Also, one of the targets of the Health 2015 public health programme is Finns' satisfaction with health service availability and functioning of health services, keeping them at least at the present level (STM 2001). The two main objectives of the National Development Plan for Social and Health Services Kaste programme (STM 2008b) is to improve the quality, effectiveness and availability of services for municipal inhabitants and to increase their involvement. Outinen et al. (2007) described the situation of quality management in social and health organisations during 2004 and evaluated the development of quality management since previous assessments conducted in 1999. The results showed that the systematic approach to quality management, documentation and the formulation of operating instructions had improved in nearly all sectors of social and health care. However, the increasing involvement of patients and their influence on the organisations' quality management and the evaluation of service quality pose a challenge in the future. (Outinen et al. 2007.) The Act on the Status and Rights of Patients (785/1992) also emphasizes patients' right to access to good quality nursing and health care.

Quality of care is defined with different concepts. It has been described as patient satisfaction (e.g. Oberst 1984, Vuori 1987, 1991a, Merkouris et al. 1999, Johansson et al. 2002, Merkouris et al. 2004), patients' perceptions and/or experiences (Larsson

& Larsson 1999, Attree 2001) or it has been described by asking patients or nurses to name indicators of quality (Redfern & Norman 1999a, 1999b, Larrabee & Bolden 2001). An indicator may be defined as an objective, measurable dimension that provides information on an important aspect of the quality of care (Attree 1993). Idvall et al. (1997) said in their literature review that clinical quality indicators are generally defined in terms of "a quantitative measure that can be used as a guide to monitor and evaluate the quality of important patient care and support service activities", as expressed in the Joint Commission on Accreditation on Health Care Organizations in the United States (JCAHO 1989). Nursing can be described as human activity, in which case the object of the study of quality can be defined based on action theory (e.g. Gaut 1984), where nursing involves human action for which prerequisites exist, carried out by an agent in an operational setting (Leino-Kilpi 1990, Leino-Kilpi et al. 1994, Leinonen 2002, Kalam-Salminen 2005, Ruotsalainen 2006).

The relationship with satisfaction and the quality of care has different perspectives. Vuori (1991a) identifies three possible functions for patient satisfaction: it can serve as an attribute of good quality care, as an indicator of good quality care, and thirdly, as a prerequisite for quality care. However, some researchers have thought that quality in the context of care is more than the consequence of patient satisfaction; it is too narrow a concept to describe the quality of care (Redfern & Norman 1990, Avis et al. 1995, Drain & Clark 2004). Satisfaction and quality have a connection; they are related to each other, but not mentioned as being exactly the same (Oberst 1984, Attree 1993). Consensus on a common conceptual definition of patient satisfaction is still lacking (Bond & Thomas 1992, Johansson et al. 2002). The concepts of patient satisfaction and patients' perceptions of quality care are frequently used alternatively, although according to Oberst (1984), there is a difference between the two concepts. Satisfaction is widely regarded as an established indicator of the quality of care reflecting the patients' views on different aspects of care (Taylor et al. 1991, Vuori 1991a, Bond & Thomas 1992, Leino-Kilpi & Vuorenheimo 1992, Merkouris et al. 1999, Johansson et al. 2002, Merkouris et al. 2004). Patient satisfaction is a result of the interaction between their expectations of care and their perceptions of the actual care (Bond & Thomas 1992, Avis et al. 1995, Leino-Kilpi et al. 1994, Dozier et al. 2001, Johansson et al. 2002). Some researchers (Petersen 1988, Thompson & Sunol 1995, Staniszewska & Ahmed 1999) suggest that all satisfaction surveys should be based on a particular patient group's expectations before attempting to measure them. Patients' expectations are influenced by past experiences, personal needs, external communications and word of mouth (Oberst 1984, Zeithaml et al. 1990, Thomson & Sunol 1995, Staniszewska & Ahmed 1999). Patient satisfaction is also affected by patients' cognitive and emotional reactions as well as psychological processes, along with situational and cultural factors (Thompson & Sunol 1995, Merkouris et al. 1999).

2.1.2 Evaluation of the quality of care

The history of defining and evaluating quality in health care probably goes as far back in time as does the history of nursing care. Florence Nightingale's early accounts of her experiences included certain quality standards for patient care. (Nightingale 1860, Bull 1992.) In the first half of the 20th century, systematic quality of care received relatively little attention (Bull 1992). Nursing has been struggling to define quality since the early 1960s (Taylor & Haussman 1988, Taylor et al. 1991, Bull 1992). Donabedian in (1966) published a model for quality health care evaluation that included the assessments of the structure, process and outcomes, which helped define the evaluation of quality more precisely. The emphasis was on process and structure rather than on outcome (Bull 1992). "Quality control" was understood in terms of importing ideas from business and industry into the world of health care (Vuori 1991b, 1993).

From 1960 onwards, the general public began to develop greater expectations about health care, and there were growing concerns about consumer protection, human rights, inflation and the rising cost of health care (Bull 1992, Merkouris et al. 1999). From the mid-1960s, "quality control" was replaced by "quality assessment". This concept was used until the mid-1970s, when it was attacked for being too passive. If there where any shortcomings in quality, the results of the measurement needed to be converted into practical corrective actions. (Vuori 1991b, Vuori 1993.) The literature on the quality of care increased rapidly during the 1970s (Bull 1992). The term "quality assurance" was coined to refer to the systematic measurements of the quality of care and to the adjustments made on the basis of the defects detected (Vuori 1991b, 1993). In the 1980s, development related to quality, evaluation and measured continued at a fast pace. This rapid growth of quality assurance was perhaps due to a combination of consumer demands, rising costs, legislation, technology, third-party payers, competition, and perhaps most of all, professional accountability (Bull 1992). The term "quality improvement" can be used to refer to all possible measures taken with a view of raising quality standards (Vuori 1991b, 1993). Since the 1990s, the patient's perspective has played an increasing role in definitions, measurements, and evaluations of nursing care (Leino-Kilpi & Vuorenheimo 1994, Thomas & Bond 1996, Merkouris et al. 1999, Clearly 2003) and as have been moved into the 21st century, nursing takes the lead in assuring that critical pieces of data are collected about patient outcomes and perceptions (OECD 2004). In Finland, the patient's point of view has been given a key role in national quality assurance guidelines as well (STM 2003, Outinen et al. 2007, STM 2008b).

In Finland, the social and health care glossary (Sosiaali- ja terveydenhuollon sanastot 1997) defines quality evaluation as operation in which the results obtained in quality measurement are compared with the quality criteria set and conclusions are drawn. The evaluation of quality of care can be quantitative or qualitative. In their review Idvall et al. (1997) found that the quantitative approach has been most commonly used, but in recent years researchers (Merkouris et al. 1999, Larrabee & Bolden 2001, Merkouris et al. 2004) have also emphasized the use of qualitative approaches. Quantitative survey approaches, although very popular and easily interpretable, may fall short in portraying patients' attitudes fully. Qualitative approaches help unveil the obvious and covert aspects of patients' satisfaction as well as probable antecedents and causes, and may help form realistic suggestions for improving the care. (Merkouris et al. 1999, Larrabee & Bolden 2001, Merkouris et al. 2004.)

Various instruments have been developed for the purposes of evaluating the quality of nursing care. Well known instruments are the Phaneuf Nursing Audit (Phaneuf 1976), the Quality Patient Care Scale (QUALPACS) (Wandelt & Ager 1974, Perälä 1995), the Monitor (Goldstone at al. 1983, Voutilainen 1992), the Patient Satisfaction Instrument (PSI) (Risser 1975) and its modification LaMonica–Oberst Patient Satisfaction Scale (LOPPS) (LaMonica et al. 1986), Abdellah and Levine's (1957) Patient Satisfaction with Nursing Care Checklist (PSNCC) and the Client Satisfaction Questionnaire (CSQ) (Larsen et al. 1979). In Finland, the Patient Satisfaction Scale (PSS) has also been used; it was further developed to gather patients' views about nursing care comparing patient satisfaction under different nursing regimens or the outcomes of particular nursing interventions (Kim 1983, Kim et al. 1993, Leino-Kilpi et al. 1993, Suhonen 2002, Suhonen et al. 2005, Suhonen et al. 2007a, 2007b).

The content of the instruments how they identify dimensions of the quality of nursing care or quality indicators, can be categorized in several different ways and from many different perspectives. The quality indicators had emerged from different approaches viz. clinical areas, generic aspects of care, specific aspects of care/nursing diagnosis and medical diagnosis. These different starting points could be influenced by research knowledge and theories/frameworks, by the opinion of the client and by the staff. (Idvall et al. 1997.) Some authors emphasize criteria related to knowledge, skills and technology, while others consider psychological criteria to be more important (Vuori 1991a).

The literature presents a whole range of quality indicators: staff skills and knowledge, competence, medical-technical competency, personal characteristics (such as friendliness, kindness, possessing a sense of humour, cheerfulness, empathy, confidence, courtesy etc.), interaction and communication skills, ability to make decisions, paying attention to patients' concerns, anticipating and meeting needs, information and education, patient focused, individualized care, taking relatives into account, physical care, responsiveness, reliability, security, availability, accessibility, acceptability, immediate admission and treatment, cost effectiveness, bureaucracy, efficiency, undesirable events, undesirable processes, ethical issues related to care, health, wellness level, results of care, patient satisfaction, physical/ social environment, continuity of care, home maintenance, possibility to take part in/ influence the care (See e.g. Donabedian 1988, Hall & Dornan 1988, Leino-Kilpi 1990, Zeithaml et al. 1990, Vuori 1991a, 1993, Leino-Kilpi et al. 1994, Attree 1993, Idvall et al. 1997, Attree 2001, Larrabee & Bolden 2001, Gunther & Alligood 2002, Suhonen & Välimäki 2003, Laschinger et al. 2004, Suhonen et al. 2005, Lynn et al. 2007, Suhonen et al. 2007a). Evaluation of the quality of care has mainly focused on hospital treatment (Leino-Kilpi & Vuorenheimo 1992, Thomas & Bond 1996, Larrabee & Bolden 2001, Johansson et al. 2002, Bostick et al. 2003, Suhonen & Välimäki 2003).

There are many problems related to measuring the quality of nursing care. The quality instruments' psychometric testing is not always sufficient, definitions and concepts are widely diverse, and most of the instruments were not generated from the patients' perspective (McDaniel & Nash 1990, Leino-Kilpi & Vuorenheimo 1992, Bond & Thomas

1992, Thomas & Bond 1996, Sitzia 1999, Dozier et al. 2001, Larrabee & Bolden 2001, Urden 2002, Suhonen & Välimäki 2003, Lynn et al. 2007). For example, Thomas and Bond (1996) found in their review that the majority of studies have used nursing instruments that were developed specifically for the study in question; also Larrabee & Bolden (2001) found in their study that the psychometrics of only 24 out of 40 instruments were reported based on a literature search (1957-2001) on instruments designed to measure patient satisfaction with nursing care. However, Leino-Kilpi & Vuorenheimo (1992) analysed 41 studies from 1974-1991 and found that most of the studies were based on instruments that had been developed earlier and were now being tested. Merkouris et al. (1999) said also that problems in measuring may be caused by uncertainty as to whether patients are in a position to distinguish separate dimensions of hospital services and how important each dimension is to the patients. Instruments for clinical evaluation should include items that are important to patients and easily differentiated and evaluated (Thomas et al. 1995, Lynn & McMillan 1999, Suhonen et al. 2007a).

The use of a quality instrument calls for certainty as to suitability for the purpose at hand of the theoretical or conceptual basis, measurement method and data gathering method. Besides, the quality instrument should be psychometrically tested, sensitive, specific, accurate, objective and feasible (Waltz et al. 1991, Leino-Kilpi et al. 1994, Perälä 1995, Thomas & Bond 1996, Dozier et al. 2001, Lynn et al. 2007.) The following have been suggested for developing quality evaluation: more versatile methods (Thomas & Bond 1996, Redfern & Norman 1999a, 1999b), combining quantitative and qualitative methods (Larrabee & Bolden 2001, Merkouris et al. 2004), focusing on factors that the patients can decide (Rosenthal & Shannon 1997, Leino-Kilpi et al. 1999, Suhonen et al. 2007a), combining patient perspective with other outcome indicators, especially with nurse-sensitive outcomes (Rosenthal & Shannon 1997, Leino-Kilpi et al. 1999, Bostick et al. 2003), expanding patient groups to take into account ethno-cultural aspects and different groups of patients, e.g. those with communication difficulties (Johansson et al. 2002).

2.1.3 Patient as evaluator of quality of care

The quality of nursing care is traditionally defined and evaluated from the perspective of professionals. Since the 1990s, the patient perspective has played an increasing role. Defining and evaluating quality from the patient's perspective has become important because of the increasing practice of applying a consumer policy viewpoint to health care while also safeguarding patients' rights and taking their views into account (e.g. Vuori 1991a, Attree 1993, Merkouris et al. 1999, STM et al. 1999, Bostick et al. 2003, STM 2003, OECD 2004, STM 2008a, 2008b). Patients' role has changed from passive to active, their knowledge level has increased and they want to take an active part in their care (e.g. Avis et al. 1995, Mercouris et al. 1999, Dozier et al. 2001, Laschinger et al. 2005).

In health care, there has been a need to focus attention on the aspects of cost benefit and cost effectiveness, and health-care professionals have raised questions about the quality of care and effectiveness of treatment (Idvall et al. 1997, Johansson et al. 2002).

Professionals' factors (Chance 1997, Johansson et al. 2002, Kvist et al. 2006, Tervo-Heikkinen et al. 2008) and the competition between hospitals has had the impact of creating a need for hospitals to use patient satisfaction as an indicator of the quality of care (Chance 1997, Dozier et al. 2001, Laschinger et al. 2005). However, there is little input from patients as to what constitutes nursing care quality; they have only evaluated it (Larrabee & Bolden 2001, Outinen et al. 2001).

Patient satisfaction with nursing care has been consistently found to be the strongest predictor of patient satisfaction with the overall healthcare experience (Thomas & Bond 1996, Idvall et al. 1997, Johansson et al. 2002, Suhonen 2002, Urden 2002, Laschinger et al. 2005). Studies have shown that patients who are more satisfied with their care are more likely to follow medically prescribed regimens, advice and directions and participate in their care (Weisman & Nathason 1985, Bond & Thomas 1992, O'Malley 1997, Stewart et al. 2000) and that they are more committed to their care (O'Malley 1997, Stewart et al. 2000). Satisfied patients are also more likely to recommend the hospital to family and friends and have a greater intention of returning to the hospital in the future (Abramowitz et al. 1987, O'Malley 1997, Urden 2002). Individualized nursing care contributes to positive patient outcomes, such as patient satisfaction, patient autonomy and perceived health-related quality of life (Suhonen 2002, Suhonen et al. 2005, Suhonen et al. 2007b).

Many factors have been shown to have an impact when patients evaluate the quality of care. Personal characteristics of patients, such as cultural background, degree of social support, previous hospital experiences (e.g. Hall & Dornan 1990, Clearly & McNeil 1988, Yellen 2003) and demographic variables, such as age, gender, marital status and education, have been found to influence patient satisfaction ratings in some studies (e.g. Cleary & McNeil 1988, Hall & Dornan 1990, Leino-Kilpi et al. 1994, Rahmqvist 2001, Johansson et al. 2002, Yellen 2003, Gonzáles et al. 2005). Patients' expectations and health status have also been found to influence their evaluations (e.g. Abramowitz et al. 1987, Cleary et. al. 1991, Leino-Kilpi et al. 1994, Arnetz & Arnetz 1996, Staniszewska & Ahmed 1999, Rahmqvist 2001, Laschinger et al. 2005, Tervo-Heikkinen et al. 2008). However, Hall and Dornan (1990) conclude that in general, socio-demographic factors have only limited influence on the general level of patient satisfaction.

Besides background factors, patients' evaluation may be influenced by difficulty on the part of the patients to discriminate nursing care from their overall experience with health care (e.g. Merkouris et al. 1999, Dozier et al. 2001, Johansson et al. 2002), by patients' tendency towards social conformity and/or dependence on nurses (e.g. Bond & Thomas 1992, Thomas & Bond 1996, Merkouris et al. 1999) and by the health care organization, such as nursing staff's work environment (Arnetz & Arnetz 1996, Johansson et al. 2002, Tervo-Heikkinen et al. 2008).

There are also some quality instruments that have been developed in Finland, such as Leino-Kilpi's "Good Nursing Care" (GNC) (Leino-Kilpi 1990, Leino-Kilpi & Vuorenheimo 1992, Leino-Kilpi et al. 1994, 1999) and Humane Caring Scale (HCS) (Töyry et al. 1998, Töyry & Vehviläinen-Julkunen 2001, Kvist et al. 2006, 2007, Tervo-Heikkinen et al. 2008).

The instruments are based on experimental data and patients' descriptions and definitions about the quality of care. In this study, one basis was the "Good Nursing Care" instrument of Leino-Kilpi, which is why it has been considered more than other instruments. The "Good Nursing Care" instrument has been developed since 1990 (Leino-Kilpi 1990, Leino-Kilpi & Vuorenheimo 1992, 1994, Leino-Kilpi et al. 1994, 1999) and it has been tested in different patients groups (Hannula 1996, Pelander & Leino-Kilpi 1993, Kalam-Salminen 1996, 2005, Wasenius 2000, Leinonen 2002, Ruotsalainen 2006, Siekkinen et al. 2008) and in different countries (Rehnström et al. 2003, Kalam-Salminen 2005). Leino-Kilpi's "Good Nursing Care" instrument is based on action theory (e.g. Gaut 1988) and is designed for hospitalized adults. Nursing involves human action carried out by an agent in an operational setting. The instrument consists of six main categories: staff characteristics, activities, preconditions, environment, procedures for admission and discharge, and empowerment strategies (Leino-Kilpi et al. 1994). Psychometric testing of the instrument has indicated that it has good content validity and internal consistency (Wasenius 2000, Rehnström 2003, Kalam-Salminen 2005, Ruotsalainen 2006). Construct validity mainly supports the theoretical construct of the instrument (Leinonen 2002, Kalam-Salminen 2005). However, in the Swedish version of the GNC the factors are different from those in the theoretical model outlined by Leino-Kilpi (1994), and some problems were also found in Ruotsalainen's (2006) study about the quality of internal medicine patient. Other problems were especially related to very positive results and the length of the instrument. Same types of problems have also been reported in other quality studies (e.g. Bond & Thomas 1992, Thomas & Bond 1996, Drain & Clark 2004). However, patients as customers are considered important sources of information for the development of new programmes and the evaluation of existing nursing services (Johansson et al. 2002).

2.2 The quality of paediatric care

For analysing the quality of paediatric care and paediatric quality instruments, a database search were carried out on the Medline (1989 - January 2008) and Cinahl (1989 - December 2007) databases. The following keywords were used: "Quality of health care OR patient satisfaction OR consumer satisfaction" AND "paediatric nursing OR child". "Paediatric nursing OR child" was used in combination because only with "child" as keyword the match was too large, and not specified to the paediatric nursing field. To narrow down the focus to children's perspective the keywords "children's perspective OR experience OR perceptions OR expectations OR views OR satisfaction" was used. At the same time a search was also made using the keywords "parents' perspective OR experience OR perceptions OR expectations OR views OR satisfaction", because the quality of paediatric care has usually been evaluated by parents. Finally, the keywords "instrument OR tool OR questionnaires OR scale OR evaluat$ OR assess$ OR measur$" was used in association with the previous ones. The material was restricted to the English language. When all these keywords were used together in different combinations, the number of matches dropped (Table 1), because most of the articles deal with quality of health care from the point of view of profession or with focus on primary care, neonatal intensive care or psychiatric care, not general hospital care. After ruling out articles occurring in more than one database or searches a total of 40 articles remained. A manual search was conducted by going through literature on paediatric nursing and reference lists of analysed articles; the manual search yielded 14 more articles. A total of 54 articles were accepted.

A more detailed analysis of the articles selected showed that among articles found as a result of the search based on children's perspective, there were also studies in which the quality of care had been evaluated by parents. The reason for this was clearly the fact that the articles had "child" or "child's satisfaction" as keywords, even though the matter had been studied from parents' point of view. All 54 articles were reviewed, yielding a total of six studies where children evaluated their own care (Appendix 1), ten studies where children and parents evaluated the care together (Appendix 2), 28 studies with only parents' perspective (Appendix 3), and ten studies focusing especially on instruments, or instrument development and one review (Appendix 4). In chapter 2.3, in addition to research articles describing the development of instruments, other instruments used in the articles and their psychometric properties are also looked at. Chapter 2.2.2 analyses also three research studies in which the quality of paediatric care is evaluated in connection with instrument development. The abstracts of these research articles have been described in Appendices 1, 2, 3, 4.

Table 1. Keywords used and the number of matches in databases 1989 – 2008

Keywords	Number of matches / Number of articles accepted in combined		Total
	Medline	Cinahl	
1. Quality of health care or patient satisfaction or consumer satisfaction	69,052	29,397	
2. Paediatric nursing or child	(6,594 or 558,634)= 562,687	(4,905 or 100,000)= 102,085	
3. Children's perspective or experience or perceptions or expectations or views or satisfaction	862	1,793	
4. Parents' perspective or experience or perceptions or expectations or views or satisfaction	1,229	1,193	
5. Instrument or tool or questionnaires or scale or evaluat$ or assess$ or measur$	2,433,618	296,719	
Combined 1+2+3+5	93 / 9	68/ 9	9+5=14
Combined 1+2+4+5	176 / 22	146 / 15	15+5=20
Combined 1+2+5	58 / 8	29 / 8	5+1=6
Manual search			14

2.2.1 Children's expectations and evaluations concerning the quality of paediatric care

In this study were wanted to find out children's expectations about the quality of care because some researchers (see Petersen 1988, Thompson & Sunol 1995, Staniszewska & Ahmed 1999) have suggested that all mapping of quality evaluation should be based on a particular patients group's expectations before attempting to measure them. No one else except the patient, in this case a child, can tell the health care professionals what is important in their care. However, as a result of the database search no studies were found charting only children's expectations of care; instead, the studies used concepts such as experiences, views, perceptions, satisfaction and voices. However, with the aid of the studies found quality indicators important for children and their views on the quality of care could be determined. In the next chapters, the importance of taking the children's own perspective into account through children's rights and legislation is first examined, followed by looking at children's views on the quality of care as well as reviewing studies in which children evaluate the quality of care together with their parents.

The past decade has seen a growing recognition of the importance of children's rights and the need to listen to and consult with children both at an international and national level (United Nations 1989, Act 785/1992, Council of Europe 1996, 1997, Act 731/1999, Department of Health 2003, Act 1221/2004, Act 72/2006, Act 417/2007). Article 12 of the United Nations Convention on the Rights of the Child (1989) states that children not only have the right to opinions of their own with regard to issues affecting them, but they also have the right to voice these opinions. The Finnish government ratified this document in 1991 (Decree on Enforcement of the Convention on the Rights of the Child 1130/1991). The European Convention on the Rights of the Child (Council Europe 1996, 1997) pointed out that, in all actions concerning children, the best interests of the child should be a primary consideration. In the United Kingdom, Children's National Service Framework (Department of Health 2003) states explicitly that hospital services should be child-centred and that children should be consulted and involved in all aspects of their care. In the US, the Health Care Quality and Outcome Guidelines for Nursing of Children and Families (Betz 2005) have been published, which can serve as the scope of practice framework for paediatric and child nursing clinicians by which to evaluate the quality of care they provide to infants, children, youth and families. A consumer version of the guidelines has also been published, based on 18 elements to assist consumers, namely families, in assessing the quality of health services that they receive (Betz 2005).

In Finland, there are acts which clearly outline that children should be seen as active partners in their care and also on decisions about their care. The Constitution of Finland (731/1999) states that children shall be treated equally and as individuals and they shall be allowed to influence matters pertaining to them to a degree corresponding to their level of development. The Youth Act (72/2006), Child Welfare Act (417/2007) and the Act on the Ombudsman for Children (1221/2004) emphasize the participation of children and the importance of hearing their views as well. The Ministry of Social Affairs and Health (STM 2008a) has issued a report which emphasizing children's rights to participate.

The 10 articles of the European Association for Children in Hospital (EACH 1988) define children's rights in hospital and emphasize a child's right to information and participation in accordance with age and maturity. In Finland, the Act on the Status and Rights of Patients (785/1992) requires that children's opinions about their medical treatment be considered in accordance with their age and maturity. Children should be seen as active partners in their care and also on decisions about their care. Children are all too often the "silent consumers of care" (Carter 1998, Hart & Chesson 1998). Today, it is increasingly accepted that children have the right to have their views taken into consideration by health care providers (Coyne 1998, Beidler & Dickey 2001, Hallström & Elander 2004, Coyne 2006a). Despite children's right to take part and make their voices heard, there is a lack of studies on the quality of paediatric nursing focusing on children and from their perspective. The database search did not reveal any studies dealing specifically with children's expectations concerning their own care. The few studies found in the search focused mainly on children's experiences (Curtis et al. 2004, Coyne 2006b), views or perceptions (Carney et al. 2003, Lindeke et al. 2006, Schmidt et al. 2007) about hospitalization in general and the determinants of adolescents' satisfaction (Freed et al. 1998).

In the studies found as a result of the search, children's experiences had mainly been charted with interviews in four studies in six (Curtis et al. 2004, Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007) or questionnaires (Freed et al. 1998, Carney et al. 2003). Carney et al. (2003) determined four different questionnaire types - structured/ unstructured and verbal/visual questionnaire - as the best method of obtaining children's views. Overall, most information was gained from verbal structured questionnaires (see also Docherty & Sandelowski 1999). The advantage of the unstructured questionnaire is that a true representation of what children thought it was important to say could be gained. The visual structured questionnaire proved to be successful at gauging the children's feelings before, during and after hospitalization (Carney et al. 2003).

Studies where evaluations have been made by parents and children together deal with cancer care (Kvist et al. 1991, Enskär et al.1997), paediatric outpatient visit (Simonian et al. 1993, Chesney et al. 2005, Witchell & Lester 2005), emergency care (Magaret et al. 2002), hospital care (Sartain et al. 2001, Battrick & Glasper 2004), neurological (Mah et al. 2006) and rheumatology care (Shaw et al. 2006a). The data have mainly been collected with questionnaires (Kvist et al. 1991, Simonian et al. 1993, Chesney et al. 2005, Witchell & Lester 2005, Magaret et al. 2002, Battrick & Glasper 2004, Mah et al. 2006, Shaw et al. 2006a), which have been modified and made user-friendly especially for the younger children. The comparison of parents and children's experiences of the quality of their care generally shows congruence. However, parents rated care significantly higher than did the children in the study of Chesney et al. (2005); also in Simonian et al. (1993) 22% of the children (n=55) expressed dissatisfaction with their visit, with 6% of these child subjects evidencing extreme dissatisfaction. On the other hand, children cared for in the emergency department reported significantly better overall satisfaction scores than their parents (Magaret et al. 2002). The perceived quality of health care for young people with juvenile idiopathic arthritis (JIA) and their parents was significantly lower than they would had liked and parents had significantly higher expectations of best practice when compared with adolescents (Shaw et al. 2006a). However, Sartain et al. (2001) found also in their study comparing hospital care to hospital at home that hospital care was exactly what the parents had expected.

Studies where care has been evaluated by children only, children have mainly reported positive experiences, views and perceptions about hospitalization. Important indicators for children during hospitalization have been nurses and nurse behaviours/activities (Freed et al. 1998, Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007) and physical and social environment (Carney et al. 2003, Curtis et al. 2004, Coyne 2006b, Lindeke et al. 2006). Schmidt et al. (2007) found that children appreciated nurses who had a positive attitude/affect, took measures to reduce pain, had an entertaining and light-hearted interaction, promoted positive well-being and sense of security, met basic needs, and interacted with them as individuals and provided comfort and support. Children have especially emphasized nurses' interaction skills, communication and provision of information in clear, appropriate language and truthful responses (Freed et al. 1998, Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006). Worst things during hospitalization are especially related to nurses' treatments and procedures causing pain and discomfort (Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007). Nurses need to be sensitive to the emotional and information needs of children (Carney et al. 2003, Curtis et al. 2004, Coyne 2006b).

Nurses' and other health care providers' characteristics are important aspects of the quality of paediatric care. Young people with juvenile idiopathic arthritis (JIA) and parents rated provider's characteristics (such as knowledge, honesty) as being more important than aspects of the physical environment or process issues (Shaw et al. 2006a); this is in line with other studies (Magaret et al. 2002, Chesney et al. 2005). Young people and their parents felt that health professionals should be highly knowledgeable about their condition and rated highly the knowledge of their current staff (Shaw 2006a). Interpersonal style was also important (Mah et al. 2006, Shaw 2006a), as Freed et al. (1998) found that adolescents' satisfaction with their visits may be more influenced by the inter-personal style of the healthcare provider than by the content of their actual discussion. Studies concerning paediatric cancer care emphasized children's and parents' positive comments on the quality of the care and excellent staff and care (Kvist et al. 1991, Enskär et al. 1997).

Quality indicators from children's and parents' perspective were also associated with health care personnel, collaboration (Enskär et al. 1997, Chesney et al. 2005), adequacy of information (Enskär et al. 1997, Sartain et al. 2001, Magaret et al. 2002, Witchell & Lester 2005) and resolution of pain (Sartain et al. 2001, Magaret et al. 2002.) Children with cancer gave negative comments about the quality of care, especially during induction therapy, and about information and painful examinations (Kvist et al. 1991), as was also the case in the study of Chesney et al. (2005).

Hospital environment is an essential part of the quality of paediatric nursing care. Carney et al. (2003) found that with children aged 4-17 years, the main theme mentioned on any occasion was the environment. The physical environment included statements about food, watching television or videos, playing games/jigsaws, beds, gowns, equipment or noise, smell or temperature, which are also mentioned in other studies (Coyne 2006b, Lindeke et al. 2006). Food was listed in both the worst and the best indicators during hospitalization (Carney et al. 2003, Curtis et al. 2004, Coyne 2006b, Lindeke et al. 2006). In the study of Chesney et al. (2005) the most common theme was that the children and teens found the doctors, nurses and clinic environment to be friendly, respectful and caring; also parents valued the child/family-friendly environment. Children valued the social environment, which included interaction with other children on the ward (Sartain et al. 2001, Carney et al.2003) as well as families being present, especially among children under school age (Lindeke et al. 2006). Children's (aged 7-14 years) fears and concerns about hospitalization focused expressly on separation from family and friends and being in an unfamiliar environment (Coyne 2006b). Children valued clinic play experiences highly (Sartain et al. 2001, Chesney et al. 2005): sufficient entertainment at hospital makes it easier for children to adapt to hospital (Enskär et al. 1997).

Some children expected more privacy, especially the older ones (Sartain et al. 2001, Battrick & Glassper 2004, Curtis et al. 2006, Lindeke et al. 2006, Mah et al. 2006). There was a consensus that sharing a ward with others more or less your own age was preferable to sharing across a wide age range (Curtis et al. 2004). Older children reported problems with environmental issues (Lindeke et al. 2006, Shaw et al. 2006a), such as there being no appropriate activities to suit their needs in the waiting area (Witchell & Lester 2005), dissatisfaction with levels of privacy or the provision of a welcoming and supportive teen-centred environment (Mah et al. 2006).

Children's background factors, such as gender (Simonian et al. 1993, Carney et al. 2003, Mah et al. 2006), age, (Simonian et al. 1993, Carney et al. 2003, Curtis et al. 2004, Lindeke et al 2006, Mah et al. 2006, Schmidt et al. 2007), chronicity, parental presence, prior admission, days in hospital (Schmidt et al. 2007) and socioeconomic status (Simonian et al. 1993) affect children's experiences/perceptions/views about hospitalization and the good things (quality indicators) and worst things (quality shortcomings) associated with it. Girls were more satisfied with their providers than boys, older children expressed greater satisfaction than did younger children (Simonian et al. 1993, Mah et al. 2006) and children from higher socioeconomic families tended to rate their paediatric visits more positively than children from a lower socioeconomic status background.The younger children were likely to respond in a socially desirable manner when they did not fully understand the multifaceted nature of instrument items. Younger children expressed less satisfaction, i.e. endorsed more negative responses than did older children, suggesting discrimination in responses and understanding of the items. (Simonian et al. 1993.)

Age is also related to children's perceptions of being well-informed (Carney et al. 2003, Curtis et al 2004), anxiety (Carney et al. 2003), nurses' advocacy behaviour, nurses' positive affect/attitude and nurses' reassurance (Schmidt et al. 2007). Older children identify the importance of verbal interaction with the nurse, nurse advocacy behaviours, and a positive affect of nurses, while younger children are more likely to identify the importance of nurses providing entertainment and humour or fulfilling basic needs (Schmidt et al. 2007). The physical hospital environment is the most important theme for older children/adolescents (Carney et al. 2003, Lindeke et al. 2006) and to males (Carney et al. 2003), whereas younger children commented on food, TV/video and games, which could be linked to home life and may suggest that they are trying to find some continuity between their hospital experience and their normal life environment. For younger children, having continuity with caregivers was important, reflecting their difficulty to tolerate separation. (Carney et al. 2003, Lindeke et al. 2006.)

Parental presence influenced children's provision of basic needs. Children with chronic illness and with previous hospitalization stressed the importance of being acknowledged by nurses more frequently than did children without a chronic illness. Those with previous hospitalization emphasized nurses' entertainment/humour activities more compared to children who had not been previously hospitalized. (Schmidt et al. 2007.) However, in the study of Freed et al. (1998) adolescents' level of satisfaction was not related to age, race or gender, or having previously seen the doctor; only having been to the clinic before was significantly associated with the visit. In their study with neurological adolescents, Mah et al. (2006) found a positive relationship between adolescent psychosocial Health Related Quality of Life (HRQL) and their satisfaction with neurological care. Mood thus has a potential effect on adolescents' evaluations of hospital services, as cognitive processing, judgement and memory can be influenced by emotional state (Mah et al. 2006).

There are differences between children's and their parents' quality assessments, highlighting their equally valid but different perspectives. Cleary (1999) has suggested that patients exert influence over quality of their care in two primary ways - exit and voice - but that children are unlikely to use the power of former. Nurses and other health professionals should therefore continue to advocate opportunities and skills training children to be able to "voice opinions" which are listened to, respected and when necessary, acted upon. Parents may not be adequate proxies for their children in quality of care surveys and it is important to obtain direct input from children when planning hospital paediatric nursing care for children. The extent to which parents can appropriately represent their child's experiences may be limited.

2.2.2 Parents' expectations and evaluations concerning the quality of paediatric care

In paediatric care, parents and caregivers can be consulted on their children's expectations and evaluations, so in this study also parents' expectations about the quality of paediatric care were examined, because some researchers (see Petersen 1988, Thompson & Sunol 1995, Staniszewska & Ahmed 1999) have suggested that all chartings of quality assessment should be based on a particular patients group's expectations before attempting to measure them. As a result of the search, only two studies where found charting parents' expectations (Cygan et al. 2002, Ammentorp et al. 2006) about care. Instead, the studies used concepts such as satisfaction, perceptions, experiences, evaluations, views, priorities, perspectives, meaning, and attitudes. Satisfaction was clearly the most commonly used concept used in parental quality assessment. However, with the help of the studies found quality indicators important for parents and their views on the quality of care of their children could be revealed.

Literature review yielded a total of 31 studies where parents had evaluated the quality of paediatric care. Parents' satisfaction, perceptions, experiences, evaluations, views, priorities, perspectives, meaning, attitudes and expectations on the quality of paediatric care have been studied in 23 cases with questionnaires (Vandvik et al. 1990, Dawson & Mogridge 1991, Brown et al. 1995, Davis 1995, Thornton 1996, Marino & Ganser 1997, Glasper et al. 1999, Homer et al. 1999, Marino & Marino 2000, Moumtzoglou et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Ygge & Arnetz 2004, Aitken & Wiltshore 2005, Ammentorp et al. 2005, Haines & Childs 2005, Miceli & Clark 2005, Ammentorp et al. 2006, Pritchard & Howard 2006), and only in seven studies with interviews (Price 1993, Callery & Luker 1996, Stubblefield & Murray 1999, Shields & King 2001, Contro et al. 2002, Stratton 2004, Heller & Solomon 2005) and in one review (Lawoko 2007). Parents' assessments about the quality of paediatric care have been studied in general hospital care (Dawson & Mogridge 1991, Price 1993, Marino & Ganser 1997, Homer et al. 1999, Marino & Marino 2000, Moumtzoglou et al. 2000, Filani 2001, Shields & King 2001, Ygge & Arnetz 2001, Co et al. 2003, Stratton 2004, Ygge & Arnetz 2004, Ammentorp et al. 2005, Miceli & Clark 2005, Ammentorp et al. 2006), emergency and outpatient care (Brown et al. 1995, Davis 1995, Glasper et al. 1999, Aitken & Wiltshire 2005), rheumatology care (Vandvik et al. 1990), haematology and oncology care (Varni et al. 2000, Contro et al. 2002, Cygan et al. 2002), neurological care (Thornton 1996), children's surgical care (Callery & Luker 1996, Pritchard & Howard 2006), transplantation care (Stubblefield & Murray 1999), cardiologic care (Lawoko & Soares 2004, Lawoko 2007) and intensive care (Haines & Childs 2005, Heller & Solomon 2005).

In their wide national wide survey in the USA Miceli and Clark (2005) focused on the issues that are most important to parents in paediatric care and with which parents are currently most dissatisfied. Dissatisfaction issues were the same regardless of whether the child was being treated in a dedicated children's hospital or general acute care hospital. Top priorities were the following: staff sensitivity to the inconvenience that a child's health problems and hospitalization may cause, the degree to which the hospital staff addresses emotional and spiritual needs, staff response to concerns/complaints made during the child's stay, staff efforts to include parents in decisions about the child's treatment, the accommodations and comfort for visitors, information provided about available facilities for close family members, staff concern to make the child's stay as restful as possible. (Miceli & Clark 2005.) The most important indicators of quality care to parents were being included in decisions about their child's care and being cared for by nurses and physicians who are clinically up-to-date and well informed (Cygan et al. 2002). The results of Ammentorp et al. (2005) showed that the greatest gap between priorities/expectations and satisfaction was in waiting time related to admission, waiting time related to fulfilment of the child's needs, and information given about the care and treatment.

Parents reported high levels of satisfaction with their children's care in general inpatient hospital (Dawson & Mogridge 1991, Marino & Ganser 1997, Marino & Marino 2000, Filani 2001, Ygge & Arnetz 2001, Co et al. 2003, Ammentorp et al. 2005, Miceli & Clark 2005, Ammentorp et al. 2006), paediatric haematology/oncology (Varni et al. 2000), rheumatology (Vanvik et al. 1990), neurology (Thornton 1996), cardiology (Lawoko & Soares 2004, Lawoko 2007), surgical (Pritchard & Howard 2006), emergency and outpatient settings (Brown et al. 1995, Davis 1995, Glasper et al. 1999, Aitken & Wiltshire 2005) and intensive care units (Haines & Childs 2005, Heller & Solomon 2005). However, in Greece parents reported low satisfaction with care in general children's hospital; satisfaction appears to be very low for the procedures of the hospital, low for the outpatient dimension and rather satisfactory for the inpatient dimension (Moumtzoglou et al. 2000).

Parents had positive perceptions and experiences of the following quality indicators during their child's hospitalization and they were most satisfied with such staff attributes as kindness, friendliness (Ygge & Arnetz 2001, Filani 2001, Ammentorp et al. 2005, 2006, Pritchard & Howard 2006), professional level (Davis 1995, Filani 2001, Haines & Childs 2005), more informal uniform (Glasper et al. 1999), care processes (Ygge & Arnetz 2001, Ammentorp et al. 2005, 2006) like staff communication (Davis 1995, Homer et al. 1999), coordination of care (Marino & Ganser 1997), discharge planning (Marino & Ganser 1997), nurses' helping behaviour meeting the parents' expectations (Thornton 1996), nursing care tailored according to their needs and preferences (Marino & Marino 2000), parent involvement (Marino & Ganser 1997, Marino & Marino 2000, Haines & Childs 2005, Pritchard & Howard 2006), quality of information (Glasper et al. 1999, Ammentorp et al. 2005, 2006), transmission of information to children (Homer et al. 1999), pain management (Aitken & Wiltshire 2005), medical treatment (Ygge & Arnetz 2001), physical comfort (Co et al. 2003) and environment (Aitken & Wiltshire 2005).

Conceptually, if structures and processes of care change, outcomes such as parental satisfaction should also change; however, in the study of Marino and Ganser (1997) this did not happen. They suggested two explanations for this: the quality of care did not change even with restructuring; nursing care had changed, but in ways that were not visible to families. Parents' evaluation of care may not be sufficiently sensitive to evaluate the impact of organizational changes in nursing practice. (Marino & Ganser 1997.) Some researchers (Price 1993, Callery & Luker 1996, Stratton 2004) suggest that qualitative methods should be used when studying the quality of paediatric nursing care from parents' perspective. Parents were reluctant to appear critical of hospital staff, but when they were given the opportunity to tell the whole story and to explain problems, parents provided detailed accounts identifying unsatisfactory aspects of care (Callery & Luker 1996).

In the qualitative studies of Price (1993) and Stratton (2004) parents described quality nursing in terms of their needs being met. Quality of care was perceived as the nurse being focused on meeting the non-technical needs of the child and parent. Non-technical needs described by parents included the need for information, diversion, socialization, sleep and decreasing child and parent stress. (Price 1993, Stratton 2004.) Besides, in the study of Heller and Solomon (2005) parents of children with life-threatening conditions emphasized that continuity of care was primarily framed in terms of quality. The interview study by Davis (1993) set in an emergency department found three main themes relating to parents' satisfaction with nurses' initial examination: staff attributes (understanding, calm, pleasant/friendly, kind/considerate, polite, gentle, cheerful, patient, helpful, good with children), communication (reassuring, good explanations, spoke directly to child, indication of waiting time) and professional (thoroughness of examination, knowledge of nurse, assessment of problem, first aid, ensured safety). Also Stubblefield and Murray (1999) found that parents call for concerned and collaborative care. Shields & King (2001) asked parents what they thought was important in the care of children at hospital in different countries; communication with staff was the theme most commonly mentioned by parents, indicating that irrespective of the culture in which the care was given, good communication between parents and staff was of paramount importance.

Dissatisfaction is caused by accessibility and staff work environment (Brown et al. 1995, Ygge & Arnetz 2001), lack of information (Vandvik et al. 1990, Filani 2001, Contro et al. 200, Haines & Childs 2005, Lawoko 2007), e.g. information about available hospital facilities (Dawson & Mogridge 1991), on the future management of the child's illness (Dawson & Mogridge 1991, Contro et al. 2002), information not adjusted to the stage of the child or the situation (Vandvik et al. 1990), information to child (Co et al. 2003), discontinuity (Vandvik et al. 1990, Haines & Childs 2005, Heller & Solomon 2005), admission process (Dawson & Mogridge 1991, Haines & Childs 2005), the speed with which their children's need were met (Brown et al. 1995), the quality of staff communication with parents (Brown et al. 1995, Davis 1995), waiting time (Davis 1995, Ammentorp et al. 2005, 2006), hospital discharge planning (Homer et al. 1999), pain management (Homer et al. 1999, Contro et al. 2002), failure to include or meet the needs of siblings (Contro et al. 2002, Haines & Childs 2005), coordination of care (Co et al. 2003) and environmental issues, such as lack of space or privacy (Davis 1995, Aitken & Wiltshire 2005, Haines & Childs 2005, Pritchard & Howard 2006).

There are many factors affecting parents' evaluation of quality of care and satisfaction with their children's care: age of children and parents (Ygge & Arnetz 2001, Lawoko & Soares 2004, Lawoko 2007), gender of parent (Lawoko & Soares 2004), type of hospital care or types of contact with the hospital (Dawson & Mogridge 1991, Moumtzoglou et al. 2000, Ygge & Arnetz 2001, Co et al. 2003, Miceli & Clark 2005), waiting time (Brown et al. 1995, Ammentorp et al. 2005, 2006), health status or parental assessment of disease severity (Vandvik 1990, Homer et al. 1999, Ygge & Arnetz 2001, Lawoko & Soares 2004), anxiety (Vandvik et al. 1990 Ygge & Arnetz 2001, Lawoko 2007), pain treatment (Ygge & Arnetz 2001), stress (Ygge & Arnetz 2001, Lawoko & Soares 2004), efficiency (Ygge & Arnetz 2001), low income (Homer et al. 1999, Lawoko 2007), employment status (Lawoko & Soares 2004), minority (Homer et al. 1999), non-English speaking (Homer et al. 1999), information to parents (Co et al. 2003) and social support (Lawoko & Soares 2004).

When measuring parents' satisfaction with hospital care, Ygge and Arnetz (2001) found the following statistically significant differences between parent groups: Parents with younger children (under 6 years old) gave high ratings for care processes and staff environment, whereas Lawoko & Soares (2004) found that parents' satisfaction with care augmented with increasing age of child; increasing parental age also predicted more satisfaction, and mothers reported lower satisfaction than fathers regarding staff attitudes. Parents of outpatients rated participation significantly more highly than parents of inpatients, parents with previous contact with the hospital rated information-routines and participation more highly than parents visiting the hospital for the first time. Parents' ratings of their child's health status had an impact on their judgement of information-illness: parents who felt less anxiety about their child's illness graded staff work environment significantly higher. Parents who were satisfied with their child's pain treatment to a great degree were significantly more positive in all areas compared to parents who were less satisfied. (Ygge & Arnetz 2001.) Results are not always uniform; for example, Cygan et al. (2002) found no relationship between severity of child's disease and parental satisfaction. Socio-demographic factors in general have only limited influence on the general level of satisfaction (Hall & Dornan 1990, Ammentorp et al. 2005, 2006). Ygge & Arnetz (2004) examined whether there were differences in quality ratings between respondents and non-respondents to a questionnaire concerning parents' views of paediatric care. The analysis revealed that respondents to the follow-up questionnaire who had never received the main questionnaire did not differ significantly from respondents to the main questionnaire in terms of ratings of key quality domains (Ygge & Arnetz 2004).

Overall, ratings of care were most closely associated with improved communication with parents and partnership in care, indicating that parents view being kept informed and involved in the care of their child as the highest priority dimensions of patient-centred quality of care (Contro et al. 2002, Co et al. 2003, Ammentorp et al. 2005, 2006). Marino and Marino (2000) found in their study that survey questions that were most strongly associated with overall satisfaction were questions about nursing practices that are collaborations between nurses and parents; satisfied parents reported nursing care that was tailored to their needs and preferences. Also, having confidence in the doctors was identified as one of the most important determinants of parent satisfaction (Ammentorp et al. 2005, 2006).

2.3 Quality instruments in paediatric care

A total of 39 different instruments to evaluate the quality of paediatric care, 27 of them developed for parents, were found in the literature review (Vandvik et al. 1990, Dawson & Mogridge 1991, Simonian et al. 1993, Budreau & Chase 1994, Brown et al. 1995, Davis 1995, Thornton 1996, Marino & Ganser 1997, Glasper et al. 1999, Homer et al. 1999, Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, Brágadottir & Reed 2002, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Ygge & Arnetz 2004, Aitken & Wilshire 2005, Ammentorp et al. 2005, Haines & Childs 2005, Miceli & Clark 2005, Ammentorp et al. 2006, Mah et al. 2006, Pritchard & Howard 2006). There were six instruments found that were designed for children (Rifkin et al. 1988, Simonian et al. 1993, Freed et al. 1998, Mah et al. 2006). In addition, some researchers had used the same or a partially modified instrument (n=6) with children and adults alike (Magaret et al. 2002, Battrick & Glasper 2004, Chesney et al. 2005, Witchell & Lester 2005, Mah et al. 2006, Shaw et al. 2006a, 2006b). For example, in the study by Magaret et al. (2002) children aged 5-12 years had the instrument read to them by investigators and their answers were recorded (Table 2).

Quality instruments have mainly been developed to evaluate paediatric general hospital care (Budreau & Chase 1994, Homer et al. 1999, Moumtzoglou et al. 2000, Schaffer et al. 2000, Filani 2001, Ygge & Arnetz 2001, Brágadottir & Reed 2002, Co et al. 2003, Battrick & Glasper 2004, Lawoko & Soares 2004, Ygge & Arnetz 2004, Ammentorp et al. 2005, Chesney et al. 2005, Miceli & Clark 2005, Witchell & Lester 2005, Ammentorp et al. 2006). In addition, there are instruments developed especially for emergency and outpatient care (Simonian et al. 1993, Brown et al. 1995, Davis 1995, Freed et al. 1998, Glasper et al. 1999, Magaret et al. 2002, Aitken & Wilshire 2005), paediatric intensive care (McPherson et al. 2000, Haines & Childs 2005), rheumatology care (Vandvik et al. 1990, Shaw et al. 2006b), haematology and oncology care (Varni et al. 2000, Cygan et al. 2002), neurological care (Thornton 1996, Mah et al. 2006), surgical care (Pritchard & Howard 2006) and to record children's perceptions of physicians (Rifkin et al. 1988). Most of these studies (n=35) came from the USA (n=18) and UK (n=7), three from Sweden and one each from Canada, Saudi Arabia, New Zealand, Iceland, Australia, Greece and Denmark.

The content of the instruments was described with a varying degree of detail in different articles. In addition to background variables, the themes in these instruments focused on professional's characteristics' (humanity, competency) and actions (interpersonal communication, parental support), contents of care (e.g. being informed, parents' involvement in care, pain management), environments (privacy, décor of wards, facilities), organization of care (access to care, continuity, staff work environment, intention to recommend or return this hospital) and parents' or/and children's overall satisfaction with the care received.

Of the studies reviewed, five were conducted to develop or test a new instrument (Rifkin et al. 1988, Simonian et al. 1993, Budreau & Chase 1994, McPherson et al. 2000, Shaw et al. 2006b), 28 of them measured the quality of care (Vandvik et al. 1990, Dawson & Mogridge 1991, Brown et al. 1995, Davis 1995, Thornton 1996, Marino & Ganser 1997, Freed et al. 1998, Glasper et al. 1999, Homer et al. 1999, Marino & Marino 2000, Moumtzoglou et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, Cygan et al. 2002, Magaret et al. 2002, Co et al. 2003, Battrick & Glasper 2004, Lawoko &

Soares 2004, Ygge & Arnetz 2004, Aitken & Wilshire 2005, Ammentorp et al. 2005, Chesney et al. 2005, Haines & Childs 2005, Miceli & Clark 2005, Witchell & Lester 2005, Ammentorp et al. 2006, Mah et al. 2006, Pritchard & Howard 2006), and three additionally reported development of instrument (Moumtzoglou et al. 2000, Varni et al. 2000, Ygge & Arnetz 2001) and 14 of the 28 used a new or modified instrument made for this study, usually without a name (Vandvik et al. 1990, Dawson & Mogridge 1991, Brown et al. 1995, Davis 1995, Glasper et al. 1999, Marino & Marino 2000, Filani 2001, Battrick & Glasper 2004, Aitken & Wilshire 2005, Ammentorp et al. 2005, Chesney et al. 2005, Haines & Childs 2005, Witchell & Lester 2005, Ammentorp et al. 2006, Pritchard & Howard 2006) and two reported testing an old, partly modified instrument (Schaffer et al. 2000, Brágadottir & Reed 2002). Three studies (Brown et al. 1995, Freed et al. 1998, Mah et al. 2006) used the same instrument, the Client Satisfaction Questionnaire (CSQ) designed by Larsen et al. (1979), and Ygge and Arnetz (2001, 2004) used the Quality of Care Parent Questionnaire based on the Quality of Care Patient Questionnaire known as the Pyramid Questionnaire widely used in Sweden, with a database comprising approximately 50,000 patients (Arnetz & Arnetz 1996,Ygge & Arnetz 2001), and Brágadottir and Reed (2002) used psychometric testing of the Pediatric Family Satisfaction Questionnaire developed by Budreau and Chase (1994). All other instruments used in the studies where only used in a single study, or the same instrument was used by the same author in different articles (see Ammentorp et al. 2005, 2006, Shaw et al. 2006a, 2006b).

Table 2. Instruments to measure the quality of paediatric care in the studies (n=35) analysed

Author, Year, Instrument	Brief Description	Sample of the Study
Rifkin et al. 1988 The Child Satisfaction Questionnaire (CSQ)	12 positively worded items, 5-point Likert scale accompanied by size-graded circles with two factors in children's satisfaction: physician-child rapport and physician communication skills	Children (n=75, 6-14 yrs)
The Physician Attribute Checklist (PAC)	7-item, yes-no answers about descriptors: happy, calm, boring, understanding, listens, special, explains	
Vandvik et al. 1990 Questionnaire (no name) -to assess parent satisfaction with hospital care	10 cm visual analogue scales (VAS). Factors: Reception to the ward, patient examination by the physician, ward atmosphere and set-up, patient examination/treatment by the physiotherapist, school/preschool, information	Parents (n=106, n=85)
Dawson & Mogridge 1991 Questionnaire (no name) -to assess parents' perceptions of the quality of care	11-item, 4-point Likert scale about admission process, history taking, information illness, planned treatment, information about facilities, nursing, overall management, procedures, future illness, medicines and overall satisfaction	Parents (n=206)
Simonian et al. 1993 The Metro Assessment of Child Satisfaction (MACS)	8-item, yes-no answers four factors: Patient Acceptance/ Trust, Patient Understanding, Physician Empathy, Physician Acceptance	Children (n=55, 6-14 yrs) Mothers (n=55)
Pediatric Satisfaction Questionnaire (PSQ)	20-item Likert scale to measure parents' satisfaction or dissatisfaction with their child's health care	

Author, Year, Instrument	Brief Description	Sample of the Study
Budreau & Chase 1994 The Pediatric Family Satisfaction Questionnaire	35-item, 6-point Likert scale, four domains: hospital service and accommodation, nursing care, medical care and child life therapy based on family-centred approach influenced by Risser's (1975) conceptual framework	Parents (n=7, n=4, n=65)
Brown et al. 1995 The Client Satisfaction Questionnaire (CSQ)	8-item, 4-point response scale: overall general satisfaction with the services received, the kind of service wanted, satisfaction with the amount of help received, the services received helped to deal with problems, the quality of service received, extent to which the clinic met needs, intentions to recommend the clinic to a friend and intentions to return if seeking help again	Parents (n=124)
Questionnaire (no name) -to assess parents' satisfaction with service in an emergency department	4-point Likert scale, four sections with several statements about: the quality of the facilities and the general organization of the ED, the quality of staff communication, the quality of care provided for children, the quality of care provided for parents	
Davis 1995 Questionnaire (no name) - to measure the perceptions of parents of children attending an Accident and Emergency department	26 questions, mixture of open-ended and closed questions, no explanations about the content	Parents (n=107)
Thornton 1996 The Adapted Patient Satisfaction Instrument (APSI) based on Risser's Instrument	25-item, 5-point Likert scale with three subscales: professional (7 items), educational (7 items), and trust (11 items)	Parents (n=20)
Marino & Ganser 1997 The Clinical Consumer Survey (CCS)	75-item interview, used only 15 items related to aspects of nursing care, 4 items related to evaluation of nursing practice and one item on which families rate the length of stay (LOS)	Parents (n=3,622)
Freed et al. 1998 Attitudes about provider's behaviours	28-item, 6-point Likert scale with two dimensions of patient expectations: the style in which provider behaved and the content of behaviour	Adolescents (n=124, 12-21 yrs)
Perceived provider's behaviours	28-item, 6-point Likert scale indicating the degree to which the provider had demonstrated the style and content during the visit	
The Client Satisfaction Questionnaire (CSQ)	8-item, 4-point response scale: overall general satisfaction with the services received, the kind of service wanted, satisfaction with the amount of help received, the services received helped to deal with problems, the quality of service received, extent to which the clinic met needs, intentions to recommend the clinic to a friend and intentions to return if seeking help again	
Glasper et al. 1999 Questionnaire (no name) - to measure parental satisfaction in paediatric outpatient nursing development unit	25-item, 4-point forced choice/Likert scales with two closed yes/no questions about signage within the hospital and department, the quality of premailed information, staff uniform/dress codes, the role of the family information centre, play therapy, waiting room facilities, ambient music, the staff photographic board, the atmosphere of department, the décor of the departments, the nurses working in the department, interaction between the team and other health care staff and parents	Parents (n=127)

Author, Year, Instrument	Brief Description	Sample of the Study
Homer et al. 1999 The Picker/Commonwealth Patient Centred Care survey (adapted version)	122 items, with 6 broad dimensions of care: information to parents, information to the patient, partnership in care, pain management, surgical issues and hospital discharge planning	Parents (n=3,622)
Marino & Marino 2000 Questionnaire (no name) - to measure hospital-wide parent satisfaction	60 items, 15 about nursing practice and one item about overall satisfaction with 5-point Likert scale	Parents (n=3,299)
McPherson et al. 2000 The Parent Satisfaction Survey for Paediatric intensive care unit (PICU)	23-item, 5-point Likert scale with three domains: hospital environment, patient care and communication	Parents (n=15, n=20, n= 66)
Moumtzoglou et al. 2000 Questionnaire (no name) - to measure satisfaction with inpatient and outpatient care	22-item, 5-point Likert scale, positive/negative response type. Satisfaction subscales were inpatient care, outpatient care and procedures	Parents (n=240)
Schaffer et al. 2000 The Parent Satisfaction Survey	18-item, 4-point Likert scale including four subcategories: Caring, Communication, Safety and Physical Setting and four open-ended questions	Parents (n=1,045)
Varni et al. 2000 The Pediatric Hematology/ Oncology Parent Satisfaction Survey (Par. SS)	24-item, 5-point Likert scale with four factors identified as General Satisfaction, Satisfaction With Staff Communication and Interaction Style, Satisfaction With Information Amount and Timeliness, and Satisfaction With the Staff's Provision of Emotional Support for the Patient and Parent	Parents (n=113)
Filani 2001 The Client Satisfaction Questionnaire (CSQ)	38 fixed response items and two open-ended questions with six domains each relating to aspects of care: Orientation-Information, Experience with nurses, Room and ward environment, Patient/client education, Diet and hospital routines and policies	Parents, mothers (n=100)
Ygge & Arnetz 2001 The Quality of Care Parent Questionnaire	63 questions, 4-point Likert scale with eight domains: information on illness, information on routines, accessibility, medical treatment, care processes, staff attitudes, participation and staff work environment, overall rating of the quality of care on a visual analogue scale (VAS) from 1 to 10	Parents (n=624)
Brágadottir & Reed 2002 The Pediatric Family Satisfaction Questionnaire (PFSQ)	35-item, 6-point Likert scale, four domains: hospital service and accommodation, nursing care, medical care and child life therapy (Budreau & Chase 1994) based on family-centred approach influenced by Risser's (1975) conceptual framework, but after factor analysis, with two main factors: nursing care and medical care	Parents (n=848)
Cygan et al. 2002 The Quality Health Care Questionnaire	33 indicators of health care and nursing care quality, 5-point Likert scale with six factors: medical care, teaching by the nurse, provider competence, choice of provider, nurse-patient interaction, convenience of appointments	Parents (n=54)

Author, Year, Instrument	Brief Description	Sample of the Study
Magaret et al. 2002 Adapted version of the Wong-Baker FACES pain Rating Scale	7 items, combination of a six-point interval scale with Wong-Baker FACES including self-report of pain, fear and anxiety levels both at presentation and at time of ED release, interpersonal interactions with doctor/ED staff and overall satisfaction (older children and parents + adequately information, waiting time, recommend or return this ED)	Children (n=60, 5-11 yrs), Children (n=41, 12-17 yrs) Parents (n=101)
Co et al. 2003 The Pediatric Inpatient Survey (PIS)	7 dimensions of inpatient care quality: partnership, coordination, information to parent, information to child, physical comfort, confidence and trust, and continuity and transition	Parents (n=6,030)
Battrick & Glasper 2004 Questionnaires (no name) - to elicit separate views of children, young people and carers on being in hospital	A number of closed questions and Likert-type scale and smiley faces. Items about ward décor, privacy, food, access to play, quality of play, manner of nurses, level of noise, pain/comfort, overall rating care	Parents (n=50) Young people (n=13, 11-16 yrs) Children (n=12, 4-10 yrs)
Lawoko & Soares 2004 The Satisfaction Children Care (SCC)	23 questions, 4-point Likert scale, questions form the Swedish version of the Pyramid Patient Questionnaire (PPQ) and the Client Satisfaction Questionnaire (CSQ) with four factors: medical care, adequacy of information, waiting time, staff attitude/support	Parents (n=1,092, n=112)
Ygge & Arnetz 2004 The Quality of Care Parent Questionnaire	58 questions, 4-point Likert scale with eight domains: information on illness, information on routines, accessibility, medical treatment, care processes, staff attitudes, participation and staff work environment, overall rating of the quality of care on a visual analogue scale (VAS) from 1 to 10	Parents (n=694, n=70)
Aitken & Wilshire 2005 Questionnaire (no name) - to explore the views of parents in their ability to care for child following discharge from a nurse-led emergency assessment unit	Likert-type scale and qualitative response boxes	Parents (n=40)
Ammentorp et al. 2005, 2006 Questionnaire (no name) - to measure parents' priorities and satisfaction in relation to paediatric care	36 -item, 5-point Likert scale with 6 dimensions of service quality: access to care and treatment, information and communication related to care and treatment, information related to practical conditions, physicians' behaviour, nurses' behaviour, access to service	Parents (n=253, n=170)
Chesney et al. 2005 Satisfaction with Child Health Care Survey (adapted version Kid's Count Survey)	12-item, 5-point Likert scale with facial expression. Items addressing relationships in the health care setting, pain and discomfort, communication issues, and willingness to tell others that facility is a good place to come to when child is ill	Children and teens (n=116, 4-19 yrs) Parents (n=115)

Author, Year, Instrument	Brief Description	Sample of the Study
Haines & Childs 2005 Questionnaire (no name) - to measure parental satisfaction with paediatric intensive care	The format reflected the family's progression through the PIC, commencing with issues relating to the child's admission, information and communication, the environment and facilities, parental support, parents' perceptions of the standard of care and the discharge processes with a Likert scale	Parents (n=110)
Miceli & Clark 2005 The Press Caney Pediatric Inpatient Survey	46-item, 5-point Likert scale with ten subscales: admissions, your child's room, meals, nursing care, test and treatments, your child's physician, family and visitors, discharge, personal issues, overall assessment	Parents (n= 50,446)
Witchell & Lester 2005 Questionnaire (no name) based on The Patient Advice and Liaison Service (PALS) standards	Yes-no answers. Key themes: information giving, children and families being active partners in care, the environment for children, who contact for help and advice	Children (n=50, 3-6 yrs) Children (n=50, 7-11 yrs) Parents (n=50)
Mah et al. 2006 The Client Satisfaction Questionnaire (CSQ)	8 items,4-point response scale: overall general satisfaction with the services received, the kind of service wanted, satisfaction with the amount of help received, the services received helped to deal with problems, the quality of service received, extent to which the clinic met needs, intentions to recommend the clinic to a friend and intentions to return if seeking help again	Adolescents (n=104, 12-18 yrs) Parents (n=104)
The Family-Centered Care survey (FCCS)	20 item to evaluate patient satisfaction and family-centred care	
The Give Youth a Voice Survey (GYV) (children)	Determines adolescents' perceptions of family-centred care. Four domains: supportive and respectful relationships, information sharing and communication, support of independence, teen-centred services	
The Measure of Processes of Care (MPOC) (parents)	20 item to measure caregivers' perceptions of family-centred care. Five domains: enabling and partnership, providing general information, providing specific information, coordinated and comprehensive care, respectful and supportive care	
Pritchard & Howard 2006 Questionnaire (no name) - to measure parental views about services in children's surgical ward	17 questions, included open and Likert-scale closed questions divided into four sections: the team, the ward, facilities, bad and good things about your stay	Parents (n=100)
Shaw et al. 2006a, 2006b The Mind the Gap Scale	22-item (adolescents) and 27-item (parents) 7-point Likert scale. Three domains: provider's interpersonal style, process of care and physical environment	Adolescents (n=308, n=301 11-18 yrs) Parents/guardians (n=303, n=286)

Psychometric evaluation of the instruments showed that internal consistency was reported for 22 instruments by using Cronbach's alpha and for nine by using item analysis (Table 3). Internal consistency was reported to be good for four instruments, but Cronbach's alpha values were not shown in the articles. Criteria of reliability were reported to be good for the instruments (Cronbach's alpha > .80) Child Satisfaction

Questionnaire (CSQ), Client Satisfaction Questionnaire (CSQ), Attitudes about provider's behaviours, Parent Satisfaction Survey for Paediatric intensive care unit, Pediatric Hematology/Oncology Parent Satisfaction Survey (Par.SS), Pediatric Family Satisfaction Questionnaire (PFSQ), Quality Health Care Questionnaire, Satisfaction Children Care (SCC), Press Caney Pediatric Inpatient Survey and Mind the Gap Scale. The stability of the instruments was established by test-retest only with three instruments: Parent Satisfaction Survey for Paediatric intensive care unit, Quality of Care Parent Questionnaire and Give Youth a Voice Survey (GYV), which is adapted for adolescents from the parental instrument Measure of Processes of Care (MPOC). Equivalence was not tested on any of instruments.

In 29 instruments, content validity for instruments was reported to have been mainly established by expert panels or by literature review, with the exception of Physician Attribute Checklist (PAC), Pediatric Satisfaction Questionnaire (PSQ), Perceived provider's behaviours, Client Satisfaction Questionnaire (CSQ) by Filani (2001), Adapted version of the Wong-Baker FACES pain Rating Scale, Satisfaction Children Care (SCC), Measure of Processes of Care (MPOC) as well as the unnamed questionnaires of Vandvik et al. (1990), Dawson and Mogridge (1991) and Davis (1995). The theoretical framework should guide item generation in instrument construction (Burns & Grove 2001). The use of a specific theoretical framework was reported in only one instrument (Budreau & Chase 1994, Brágadottir & Reed 2002). Literature review was reported to be used in instrument construction for 14 instruments (see Table 3). Construct validity was established for 12 instruments, by factor analysis for Child Satisfaction Questionnaire (CSQ), Metro Assessment of Child Satisfaction (MACS), Client Satisfaction Questionnaire (CSQ), Attitudes about provider's behaviours, Pediatric Hematology/Oncology Parent Satisfaction Survey (Par.SS), Quality of Care Parent Questionnaire, Pediatric Family Satisfaction Questionnaire (PFSQ), Quality Health Care Questionnaire, Satisfaction Children Care (SCC), Press Caney Pediatric Inpatient Survey, Mind the Gap Scale and the questionnaire of Moumtzoglou et al. (2000) to measure satisfaction with inpatient and outpatient care. Criterion validity was not tested at all; many researchers gave lack of available validated instruments for comparison as the reason for this.

The major limitations in the use of these instruments were insufficient testing of validity and reliability. In their review, Latour et al. (2005) examined the content and characteristics of satisfaction surveys for the development of parents' satisfaction questionnaire in paediatric intensive care. They found that the use of parent satisfaction surveys in paediatric intensive care is not well documented, but most questionnaires showed sufficient results on reliability and validity. Another problem associated with the indicators was the lack of definition of background concepts related to evaluation of quality of care, i.e. what the instrument measures (e.g. Bond & Thomas 1992, Leino-Kilpi & Vuorenheimo 1992, Sitzia 1999, Suhonen & Välimäki 2003, Melender et al. 2006). After all, caregivers have not developed instruments and methods to measure the processes and outcomes of paediatric care, as is the case in adult care (Beal et al. 2004).

Table 3. Psychometric Properties of the Instruments (n=39)

Author, year	Instrument	Reliability testing				Validity Testing		
		Internal Consistency		Stability	Equivalence	Content Validity	Criterion Validity	Construct Validity
		Alpha Coefficient	Item analysis					
Rifkin et al. 1988	The Child Satisfaction Questionnaire (CSQ)	.89	Item-total correlation	-	-	Literature review Expert group	-	Factor analysis
	The Physician Attribute Checklist (PAC)	.70	Item-total correlation	-	-	-	-	-
Vandik et al. 1990	Questionnaire (no name)	-	-	-	-	-	-	-
Dawson & Mogridge 1991	Questionnaire (no name)	-	-	-	-	-	-	-
Simonian et al. 1993	The Metro Assessment of Child Satisfaction (MACS)	.26 - .68	Item-total correlation	-	-	Expert Group	-	Factor analysis
	Pediatric Satisfaction Questionnaire (PSQ)	-	-	-	-	-	-	-
Budreau & Chase 1994	The Pediatric Family Satisfaction Questionnaire	-	-	-	-	Expert group Pilot test	-	-
Brown et al. 1995	The Client Satisfaction Questionnaire (CSQ)	.86	Item-total correlation	-	-	Expert group	-	Factor analysis
	Questionnaire (no name)	-	-	-	-	Expert group	-	-
Davis 1995	Questionnaire (no name)	-	-	-	-	-	-	-
Thornton 1996	The Adapted Patient Satisfaction Instrument (APSI) based on Risser's Instrument	Tested, no value	-	-	-	Expert group	-	-
Marino & Ganser 1997	The Clinical Consumer Survey (CCS)	.78	-	-	-	Expert group	-	-
Freed et al. 1998,	Attitudes about provider's behaviours	.79 - .86	-	-	-	Literature review	-	Factor analysis
	Perceived provider's behaviours	.70 - .76	-	-	-	-	-	-
	The Client Satisfaction Questionnaire (CSQ)	.86	Item-total correlation	-	-	Expert group	-	Factor analysis
Glasper et al. 1999	Questionnaire (no name)	-	-	-	-	Pilot test	-	-
Homer et al. 1999	The Picker/Commonwealth Patient Centred Care survey (adapted version)	-	-	-	-	Expert group Pilot test	-	-

Author, year	Instrument	Reliability testing				Validity Testing		
		Internal Consistency		Stability	Equivalence	Content Validity	Criterion Validity	Construct Validity
		Alpha Coefficient	Item analysis					
Marino & Marino 2000	Questionnaire (no name)	-	-	-	-	Literature review	-	-
McPherson et al. 2000	The Parent Satisfaction Survey for Paediatric intensive care unit (PICU)	.83	-	Test-retest	-	Literature review Expert group Pilot test	-	-
Moumtzoglou et al. 2000	Questionnaire (no name) to measure satisfaction with inpatient and outpatient care	.73	Item-total correlation	-	-	Pilot test	-	Factor analysis
Schaffer et al. 2000	The Parent Satisfaction Survey	-	-	-	-	Literature review Expert group	-	-
Varni et al. 2000	The Pediatric Hematology/Oncology Parent Satisfaction Survey (Par.SS)	.96	Item-total correlation	-	-	Literature review Expert group	-	Factor analysis
Filani 2001	The Client Satisfaction Questionnaire (CSQ)	-	-	-	-	-	-	-
Ygge & Arnetz 2001	The Quality of Care Parent Questionnaire based on The Quality of Care Patient Questionnaire = Pyramid Questionnaire	>.70	Item-total correlation	Test-retest	-	Literature review Expert group	-	Factor analysis
Brágadottir & Reed 2002	The Pediatric Family Satisfaction Questionnaire (PFSQ)	.83	-	-	-	Literature review Expert group	-	Factor analysis
Cygan et al. 2002	The Quality Health Care Questionnaire	.84	-	-	-	Literature review Expert group	-	Factor analysis
Magaret et al. 2002	Adapted version of the Wong-Baker FACES pain Rating Scale	-	-	-	-	-	-	-
Co et al. 2003	The Pediatric Inpatient Survey (PIS)	>.70	Item-total correlation	-	-	Literature review Expert group	-	-
Battrick & Glasper 2004	Questionnaire (no name)	-	-	-	-	Pilot test	-	-
Lawoko & Soares 2004	The Satisfaction Children Care (SCC)	.86 -.93	-	-	-	-	-	Factor analysis

Author, year	**Instrument**	**Reliability testing**				**Validity Testing**		
		Internal Consistency		Stability	Equivalence	Content Validity	Criterion Validity	Construct Validity
		Alpha Coefficient	Item analysis					
Ygge & Arnetz 2004	The Quality of Care Parent Questionnaire based on The Quality of Care Patient Questionnaire = Pyramid Questionnaire	.71-.76	Item-total correlation	Test-retest	-	Expert group	-	Factor analysis
Aitken & Wilshire 2005	Questionnaire (no name)	-	-	-	-	Pilot test	-	-
Ammentorp et al. 2005, 2006	Questionnaire (no name)	.44 -.91	-	-	-	Literature review	-	-
Chesney et al. 2005	The Satisfaction with Child Healthcare Survey (adapted version Kid's Count Surveys)	-	-	-	-	Pilot test	-	-
Haines & Childs 2005	Questionnaire (no name)	-	-	-	-	Literature review	-	-
Miceli & Clark 2005	The Press Caney Pediatric Inpatient Survey	.98		-	-	Tested	-	Factor analysis
Witchell & Lester 2005	Questionnaire (no name) based on The Patient Advice and Liaison Service (PALS) standards	-	-	-	-	Expert group	-	-
Mah et al. 2006	The Client Satisfaction Questionnaire (CSQ)	.86	Item-total correlation	-	-	Expert group	-	Factor analysis
	The Family-Centered Care Survey (FCCS)	Tested, no value	-	-	-	Tested	-	-
	The Give Youth a Voice Survey (GYV)	Tested, no value	-	Test-retest	-	Tested	-	-
	The Measure of Processes of Care (MPOC)	Tested, no value	-	Test-retest	-	-	-	-
Pritchard & Howard 2006	Questionnaire (no name)	-	-	-	-	Literature review Pilot test	-	-
Shaw et al. 2006a, 2006b	The Mind the Gap Scale	.91-.94	Item-total correlation	-	-	Literature review Expert group	-	Factor analysis

There is a shortage of instruments developed and designed specifically for children themselves (Stewart et al. 2005), especially to evaluate the quality of paediatric care, or more specifically nursing. All seven instruments - Child Satisfaction Questionnaire (CSQ), Physician Attribute Checklist (PAC), Metro Assessment of Child Satisfaction (MACS), Attitudes about provider's behaviours, Perceived provider's behaviours, Client Satisfaction Questionnaire (CSQ), GiveYouth a Voice Survey (GYV) - designed to be used only by children themselves were mainly designed to evaluate children's satisfaction with physicians and especially aimed at adolescents, whose cognitive ability to complete instruments is at the same level as adults' (Piaget 1952). There is a lack of instruments designed for school-age or younger children. Rifkin et al. (1988) found in their study that the relationship between age and negatively phrased items was largely accounted for by children less than 12 years of age. The tendency of younger children (under 12) to endorse negative items suggests that they had difficulty understanding these items and simply affirmed them. An alternative explanation is that the younger children were less satisfied with their medical care (see also Simonian et al. 1993). Moreover, younger children were more likely to endorse all items strongly (Rifkin et al. 1988).

2.4 Summary of literature review

In conclusion, dictionary definitions of quality are clear and describe quality as a general phenomenon, whereas the definition of quality becomes very complex when describing the quality of care. As a concept, quality is highly regarded, and good, high-quality care should always be the aim in nursing. One of the major obstacles in this effort is represented by the immense diversity of concepts and definitions of quality, which is further compounded by the lack of properly tested instruments. The definition of quality of care is always affected by who is defining it, from which perspective, when, where, how and in what way. Quality of care always contains both medical care and nursing, and it is difficult for patients to tell them apart, or patients may not be able to or they may not want to evaluate the clinical, medical or technical areas of care (e.g. Johansson et al. 2002). However, previous studies support the notion that the nursing care provided by nurses is regarded as the most important factor in patients' evaluations of the quality of care (e.g. Thomas & Bond 1996, Marino & Marino 2000, Johansson et al. 2002).

Patients have an increasingly important role as evaluators of the quality of care. In paediatric care, it is usually the parents and caregivers who are consulted on their children's experiences or who evaluate the quality of paediatric care. In paediatric nursing, satisfaction has been the most commonly used concept describing quality, although many different concepts, mainly not defined, have been used. The main findings of the studies were similar; children and their parents have mostly been satisfied with their care. Dissatisfaction has been caused by insufficient information, problems in interpersonal communication and environmental issues. The problem is that the studies have used different instruments, and there is scanty information about the development process and the content of some instruments, and the evaluation of the validity and reliablility of the analysed instruments was inconsistent. Developing the quality of paediatric nursing care results with the same instruments at different times would have given more specific information than using the developed instrument perhaps only once. Besides, studies have been conducted in different countries, mainly in the USA, where the entire health care organization is different from that in Finland. The cultural aspects should be considered more carefully, which would be possible by using the same tested instruments, taking the cultural aspect into account as well. In the analysed studies the sample sizes varied a lot, from 4 (Price 1993) parents in qualitative studies to 50,446 (Miceli & Clark 2005) in quantative studies.

However, the extent to which parents can appropriately represent their child's experiences may be limited. The best way to understand children's experiences is to ask them, even though it is possible that they are difficult to investigate because of their developmental level. There is a lack of studies where children evaluate the quality of their care, and there are only few instruments designed for assessment of paediatric nursing, or they have not been published. When using children as informants, nearly all sample sizes were under one hundred, which limits the generalization of results in nursing practice. The age range of the children varied a lot even within the same studies (Table 2), which could affect the validity and reliability of the results when using the same instrument. However, children have a right to opinions of their own with regard to issues affecting them, but they also have the right to voice these opinions, and evidence suggests that the promotion of children's autonomy leads to enhanced wellness and improved health outcomes. Therefore health professionals should commit themselves to children's perspective in service delivery: this would lead to more focused and more relevant paediatric nursing care for children.

In this study the focus of interest is on quality evaluation of paediatric nursing care by the children themselves. At the beginning of the study, children's expectations concerning the quality of paediatric care were charted, and a quality instrument aimed at school-age children was developed based on them (see e.g. Thompson & Sunol 1995, Staniszewska & Ahmed 1999, Dozier et al. 2001). In the end, hospitalized school age children evaluated the quality of paediatric nursing care by using this developed instrument.

3 PURPOSES OF THE STUDY AND RESEARCH QUESTIONS

The purpose of this three-phase study was to describe children's expectations and evaluations concerning the quality of paediatric nursing care and to develop a quality instrument for hospitalized school-age children. The ultimate aim is to improve the quality of paediatric nursing care in hospital from children's perspective. To achieve this aim, the research process was divided into three phases. Firstly, the purpose was to explore children's expectations concerning the quality of paediatric nursing care and describe elements of quality in children's drawings of an ideal hospital. Secondly, the purpose was to develop an instrument for evaluating the quality of paediatric nursing care from children's perspective based on their expectations and explore the psychometrics of the instrument. Thirdly, the purpose was to evaluate the quality of paediatric nursing care as perceived by children aged 7-11 in Finland. The phases of the study are described in Figure 1. More specifically, the following research questions were addressed:

1. What are children's expectations concerning the quality of paediatric nursing care? (Paper I, II)
2. What is the quality of paediatric nursing care in Finland? (Paper III, IV)
3. What are the psychometrics of the "Child Care Quality at Hospital" Instrument (CCQH)? (Paper V, summary)

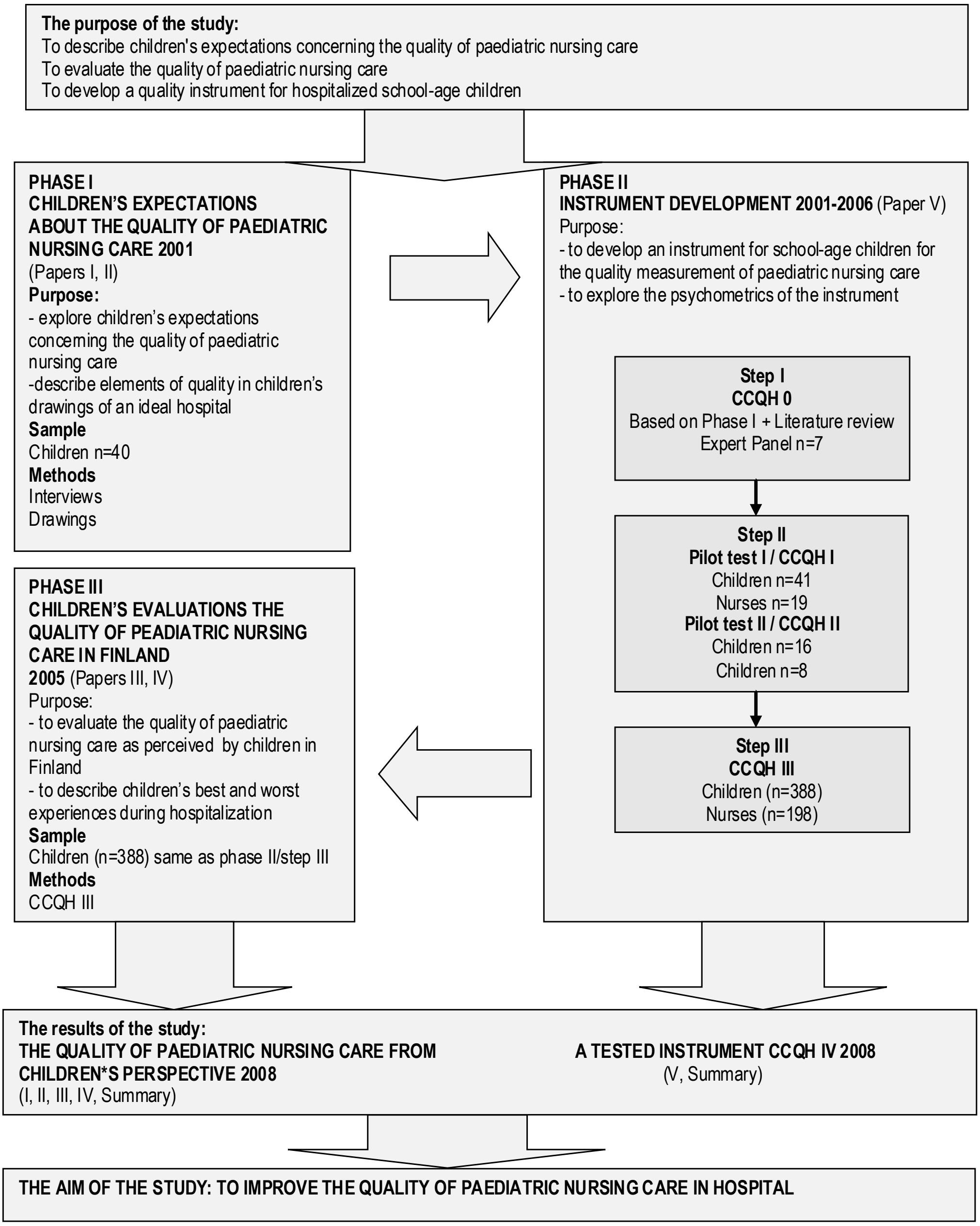

Figure 1. The study phases

4 METHODOLOGY

This study is concerned with the quality of paediatric nursing care from children's perspective and development of a quality instrument for hospitalized school-age children. The work was carried out in three phases between 2001 and 2008 by using different methods (see Figure 1).

In **Phase I,** the purpose was to explore children's expectations concerning the quality of paediatric nursing care and to describe elements of quality in children's drawings of an ideal hospital. To achieve this, the first phase of study was based on interviews with children (Paper I) as well as on drawings made by children (Paper II).

In **Phase II**, the purpose was to develop an instrument for evaluating the quality of paediatric nursing care from children's perspective based on their expectations (Paper I, II) and to explore the psychometrics of the instrument (Paper V). The results of the first phase, earlier studies and literature review served as structural basis for the development of the questionnaire for phase II.

In **Phase III**, the purpose was to evaluate the quality of paediatric nursing care and to describe children's best and worst experiences during hospitalization as perceived by children aged 7-11 in Finland (Paper III, IV). To achieve this, the instrument developed in phase II was used; at the same time, this large sample was also used for psychometric evaluation of the instrument.

The following chapters present the sampling and settings, data collection, data analysis and ethical questions of each phases of the study.

4.1 Sampling and settings

In **the first phase,** the data were collected through theme interviews and children's drawings from 20 preschool-age children (4 to 6 years) and 20 school-age children (7 to 11 years). In both age groups, one half of the children had insulin-dependent diabetes mellitus (IDDM); the other children were treated on surgical ward for various problems, such as fractures. (Paper I, II.) Children under four years of age were excluded because it is not until at four years that a child can relate memories from separate events to each other; in addition, at four a child has been speaking for about two to three years and begins to master the construct of language (Piaget 1952, Stern 1992). Similarly, children older than 11 were excluded because their thinking is closer to a more adult way of thinking (Piaget 1952).

The children were selected by nursing staff on the ward and the diabetes nurse using the following criteria: age 4-11 years; at least an overnight stay in the hospital for children from the surgical ward; and willing to participate in the study. All subjects were patients of the paediatric department of a Finnish university hospital. There were 28 boys and

12 girls; most were children aged four (n=10), 32 children had previous hospitalization experiences. The exact demographic data for the children are shown in Paper I as well as in Table 4. The final sample comprised 40 interviews and 35 drawings, because some children were not able to draw owing to fractures or did not want to draw.

In **the second phase**, data were collected with different versions of the instrument developed CCQH 0, CCQH I, CCQH II, CCQH III (see more on data collection 4.2), content validity testing questionnaire (Perälä 1995) and with interviews with hospitalized school-age children (Paper V).

In this study phase, a decision was made to develop an instrument for care quality evaluation only for school-aged children, even though the expectations of children under school age were charted as well. According to Piaget (1952), children aged 7 to 11 years are at the stage of concrete operations, that is, they can produce more information about their experiences than those at the preoperational stage, i.e. 2-6 years of age. The age of 7 is a major turning point in the development of children. At this age their language expands, they acquire reading skills and they start to distinguish different points of view. (Selman 1980, de Leeuw et al. 2004.) The lower age limit for inclusion in the sample was 7 years, which is the age when children start school in Finland. In the main data collected in spring 2005, at least theoretically, the youngest children aged 7 years who started school in the autumn able to read and write. Similarly, children older than 11 were excluded because their thinking comes closer to a more adult way of thinking. The age span 6-14 represents a period of marked change in cognitive development, including children's ability to interpret and process events in their environment (Piaget 1952).

The blueprint of the instrument (CCQH 0) was submitted for review and critique by a panel consisting of four paediatric nursing experts, a special teacher for children with difficulties in reading and spelling, a paediatrician and a statistician. After that, the second version CCQH I was pilot-tested in a sample of 41 hospitalized children, 97% of whom responded. The mean age of the respondents was nine years. Two thirds of the children were in hospital because of an emergency: 46% stayed in hospital for one night. All children were patients of the paediatric wards of two regional hospitals and two central hospitals. At the same time, the instrument was evaluated ward by ward by 19 volunteer nurses from five paediatric wards using an adapted version of the content validity testing questionnaire (Perälä 1995).

The revised CCQH II instrument was pilot-tested among IDDM children aged 8 to 11 (n=16) attending a camp for diabetics. Half of the children were boys and their mean age was 10 years. Half of the children (n=8) were also briefly interviewed as part of the assessment of the instrument. The pilot tests were only used in the instrument development process; the results have not been published. After this data were collected with the developed instrument CCQH III in phase III. The data from the third phase were also used in psychometric testing and further instrument development process.

In **the third phase**, data were collected with the CCQH III questionnaire between January and May 2005 from the paediatric clinics of the five university hospitals in Finland (Paper III, IV). The intensive care, psychiatric, neurological and outpatient wards for paediatric patients were excluded. A total of 23 paediatric and surgical wards for children were included. The data were collected in proportion to the number of children admitted to each ward on the basis of statistics for the previous year. More data were thus collected from surgical wards than oncological wards.

The inclusion criteria for the children to participate in the study were: 1) age 7-11 years, 2) at least an overnight stay in hospital, 3) Finnish-speaking, 4) in reasonably good health, and 5) ability to fill in the questionnaire either alone or with parents' help. The children answered the questions as independently as possible before being discharged. A total of 388 anonymous responses were obtained, with an overall response rate of 91%. There were 51% boys and 49% girls. Half of the children (50%) were discharged from surgical wards, the rest from paediatric wards. The respondents' mean age was nine years. Over half of the cases were emergency admissions (68%) and over half of the children had been in hospital previously (58%). Over one third (37%) stayed in hospital for more than two days (Table 4).

At the same time, nursing staff from the same wards evaluated the content validity (Perälä 1995) of the CCQH III questionnaire. The goal was to reach at least 25% of the regular nursing staff (n=642) on these wards. Of the 321 questionnaires distributed, 208 were returned, ten of which were incompletely filled. This gave a response rate of 62%, representing 31% of regular staff (n=198). The majority, 85%, of the respondents were registered nurses; the remaining 15% were assistant nurses. Their work experience ranged from three months to 36 years (mean 13,6). The majority of the respondents had experience of quality development (88 %), but only 48% had experience of quality development from children's perspective, mainly related to different pain care projects.

Table 4. Demographic characteristics of children in different phases

	Phase I		Phase II				Phase III	
			Pilot I		Pilot II			
	n=40		n=39-41		n=16		n=378-388	
	f	%	f	%	f	%	f	%
Gender								
Girl	12	30	20	49	8	50	188	49
Boy	28	70	21	52	8	50	198	51
Age in years								
4	10	25						
5	6	12,5						
6	4	10						
7	4	10	6	15			61	16
8	6	15	9	22	1	6	71	18
9	1	2.5	12	29	3	19	81	21
10	8	20	11	27	5	31	80	21
11	2	5	3	7	7	44	94	24
Disease/reason for hospitalization								
Diabetes	20	50			16	100		
Surgical	20	50	22	56			193	50
Paediatric			17	44			195	50
Previous hospitalization								
Yes	32	80	23	56			223	58
No	7	17.5	13	32			146	38
Do not know/remember	1	2.5	5	12			17	4
Admission								
Scheduled			13	32			123	32
Emergency			27	68			263	68
Days of hospitalization								
1			19	46			156	41
2			13	33			86	22
3			3	7			46	12
4			3	7			23	6
≥ 5			3	7			72	19
Hospital Room								
Private			21	53			113	29
Private and shared with other children							100	26
Room shared with other children			19	47			171	45
Primary Nurse								
Yes			18	44			192	51
No			11	27			75	20
Do not know			21	29			111	29
Parents present during hospitalization								
All time			18	44			135	35
During daytime			16	39			228	59
Some hours			5	12				
During admission and discharge			2	5			21	6

*Phase II/step III and phase III the children are the same

4.2 Data collection

In **the first phase**, data were collected by interviews (Paper I) and drawings (Paper II). The interview themes (Appendix 5) were based on earlier studies on the topic (e.g. Rifkin et al. 1988, Freed et al. 1998, Simonian et al. 1993, Budreau & Chase 1994, Schaffer et al. 2000) and a previously presented definition of the quality of nursing care from patients' perspective (Leino-Kilpi & Vuorenheimo 1992, 1994, Leino-Kilpi et al. 1994, 1999). The quality categories of the "Good Nursing Care" instrument of Leino-Kilpi i.e. nurse characteristics, nursing activities and nursing environment, were the thematic entities covered in children's expectations related to the quality of paediatric nursing care. However, with children the concept "good care" was used instead of "quality". The background information collected about the children (age, gender, reason for hospitalization, previous hospitalization), interview situation, and what and in what order the children drew is shown in Appendix 6.

At the same time, data were also collected through the children's drawings (Paper II). Children may speak more clearly and openly through their drawings than what they are willing or able to express verbally. Drawing facilitates telling about events or concepts children might otherwise find difficult to describe (e.g. Deatrick & Faux 1991, Barker & Weller 2003, Driessnack 2005). The children were asked to draw what they thought was the ideal hospital and also to tell what they were drawing. To help them with the drawing task, the children were asked the following questions: What do you think an ideal hospital for children should look like? Who or what would you like there to be at the ideal hospital for children? Prior to the actual study, the themes and the instructions of the drawings were tested by means of eight pilot interviews with children of similar characteristics as those included in the sample. The pilot was used to test the interview questions and the instructions for the drawings; based on the results, the word 'good' was used instead of 'quality', for example.

The data were collected by interviewing the diabetic children as part of their care in the outpatient clinic (n=11) of the hospital or in their homes (n=9) and the other children on the surgical ward during hospitalization. The interviews were carried out either in patient rooms (n=5) or in the examination room (n=15), allowing the parents to be present if they or their child so wished. Five children did not draw because of fractures or other reasons.

In the **second phase,** data were collected by using different versions of the developed "Child Care Quality at Hospital" instrument (CCQH 0, CCQH I, CCQH II, CCQH III), an adapted version of a content validity testing questionnaire by Perälä (1995) and with interviews (Paper V). The instrument was developed to measure the quality of paediatric nursing care; "paediatric nursing care" was omitted from the name of the instrument to keep it as short as possible. In the development of the questionnaire drawn up on the basis of the results of the first phase, it was possible to design the instrument so as to be more sensitive to respondents' meanings and interpretations (Coyle & Williams 2000). Besides, in developing the instrument, earlier literature and Leino-Kilpi's "Good Nursing Care" quality categories were utilized: nurse characteristics, nursing activities and nursing environment (Leino-Kilpi & Vuorenheimo 1992, 1994, Leino-Kilpi et al. 1994, 1999), which have also been tested with school-aged children previously (Pelander & Leino-Kilpi 1993). Quality indicators used in previous studies on the quality of paediatric nursing were also used in the development work (Appendix 7). The questionnaire was developed during three steps (the phases named in Paper V). Demographic background data were collected on gender, age, reason for hospitalization, duration of stay, previous hospitalization, parents' presence during the stay, hospital room, appointment of primary nurse and scheduled / unscheduled admission. They were the same in all steps, but in pilot test II the children in the camp for children with diabetes answered only background variables concerning age and gender (Table 4).

Step I

The first version of the instrument, "Child Care Quality at Hospital" CCQH 0 (Appendix 8) was developed on the basis of earlier research (Appendix 7) as well as on what children, as patients, considered as being the most important quality factors in nursing care (Phase I). The CCQH 0 consisted of 66 items, two open-ended questions and a drawing task. An expert panel (n=7) gave feedback based on which the content and wording of the CCQH 0 items were revised. A total of thirteen items were deleted on this basis and four items added, and the wording of one item was revised. Besides, the items under the heading of nurse characteristics were revised to include two opposite adjectives. This was to test children's understanding of the items, the consistency of their answers and their competence to answer the items.

Step II

The instrument's second version, "Child Care Quality at Hospital" CCQH I (Appendix 9), consisted of 60 items, two open-ended questions and a drawing task. The nurses evaluated the instrument using an adapted version of content validity testing by Perälä (1995, Appendix 10). The nurses were asked to judge and quantify the validity of the items and subcategories on a scale from one to four for relevance, clarity and concreteness, to indicate whether or not (yes/no) the subcategory belongs to this particular main category; whether or not the subcategory measures quality, and whether or not there is any overlap between the different subcategories. Furthermore, the nurses evaluated whether or not (yes/no) the main category measured the quality of paediatric nursing, and on a scale to one to four, whether the subcategories covered the main categories. The nurses (n=19) answered together by ward (n=5). Based on the children's answers and the assessments of nurses, the instrument was again revised; particularly the main category of nursing environment and the preset response options to the environment items were modified from a five-tiered agreement/disagreement scale using teddy-bear icons to a four-tiered one. On the basis of previous studies, a decision was made to limit the number of response options to three and four and to represent them graphically as well (smileys and teddy bears) so as to make the instrument more suitable for children and thus increase the reliability of their answers (Holaday & Turner-Henson 1989, Rebok et al. 2001, Borgers et al. 2004). In addition, the options "I have not needed help" and "I have not been pain" were added to the battery of items in the subcategory concerning physical care and treatment.

Following changes, the third version of "Child Care Quality at Hospital" (CCQH II, Appendix 11) consisting of 59 items, three open-ended questions and a drawing task, was pilot-tested again at a summer camp for children with insulin-dependent diabetes mellitus. After that the interview was used to evaluate item clarity, item format and the content of items from children's perspective. One item was consequently reworded.

Step III

The instrument's fourth version, "Child Care Quality at Hospital" CCQH III (Appendix 12), consisted of 58 items divided into three main quality categories: nurse characteristics (5 subcategories, 11 items: 4 pairs of opposing items, 2 positively worded items, 1 negatively worded item), nursing activities (5 subcategories, 28 items), and environment (3 subcategories, 19 items); three open-ended questions, consisting of two sentence completion-type open-ended questions and children's overall evaluation about their care at hospital with a school grade from 4 to 10 and a drawing task. In the CCQH III the items concerning nurse characteristics and nursing activities are rated with a three-point Likert scale to measure frequency, using both words and pictures of faces (1= never = ☹, 2 = sometimes = 😐, 3 = always = ☺). The nursing environment items are rated with a 4-tiered agreement/disagreement scale using teddy-bear icons: "fully agree" = four crossed-out teddy bears, "somewhat agree" = three crossed-out teddy-bears, "somewhat disagree" = two crossed-out teddy-bears and "fully disagree" = one crossed-out teddy-bear. All items were positively worded. The higher the score, the better the perceived quality of nursing care. The nurses evaluated the CCQH III using an adapted version of the content validity testing method of Perälä (1995) (Appendix 13, see step II). See Appendix 14 for more detailed information about the development of the content/items of the "Child Care Quality at Hospital" CCQH Instrument.

In the **third phase**, data were collected with the instrument's fourth version CCQH III (Appendix 12, Paper III) and an adapted version of the content validity testing method (Perälä 1995, Appendix 13). (More detailed information about the above instruments in Phase II). There were three open-ended questions at the end of the instrument. Two out of three open questions were sentence completions in which children were asked to describe their best and worst experiences during hospitalization. The sentences were: "In my view the best thing about hospital has been …" and "In my view the worst thing about hospital has been …". Sentence completion was used in Paper IV. It is the most widely used completion technique, with sentence stems designed to elicit responses towards some event in which the researcher is interested (Polit & Hungler 1999). By asking the children to give their best and worst hospital experience the aim was on the one hand to look for children's quality indicators and quality shortcomings, i.e. what had been good about the care, and the aspects their worst experiences were associated with in order to eliminate and reduce them and at the same time to boost the strength sources of best experiences. As such, the aim was to improve the quality of paediatric care. The drawing material collected in the third phase is not reported as part of this thesis.

4.3 Data analysis

In **the first phase**, data analysis of interviews and drawings was based on inductive qualitative content analysis (Miles & Huberman 1994). At first, the recorded interviews were transcribed. Expressions or sentences that conveyed a clear meaning relevant to the research served as units of analysis. The interviews were classified according to the main interview themes. In categorizing the material, issues denoting the same feature were grouped into the same category and the category was given a title to describe the contents. Finally, subcategories with similar contents were combined to form the generalized categories nurse, nursing activities and environment. (Paper I.)

There were no set rules for the use of drawings for research purposes, particularly in this study where there was no proper instrument, as the children were simply asked to produce a spontaneous drawing of an ideal hospital. The analysis was based on inductive qualitative content analysis (Miles & Huberman 1994). The units of analysis in the drawings were the things appearing in the drawings, their shapes and colours, the people as well as their expressions and activities (Burns & Grove 2001). The drawings were not interpreted because they were not used as a diagnostic or therapeutic tool (e.g., DiLeo 1983, Kelley 1985). While drawing the children also explained what they were drawing. The children's own words and also the order of their drawings were written down. Analysis was started out by looking at the drawings one by one and making notes of what they depicted, such as a "big white hospital". Next, items that belonged together were combined into the same subcategory. Then, similar subcategories were grouped under broader categories. Finally, the main categories were given names describing the joined subcategories. Children's points of view (hospital building, hospital surroundings, patient room, separate items, parents) in their drawings were also analysed; at the same time, the number of people appearing in the drawings made from these different vantage points was counted. (Paper II.)

In the **second phase,** the instrument was developed during three steps. *In step I,* the expert group assessments about relevance, clarity and content of the items of the CCQH 0 were used, together with comments on response alternatives and the appearance of the questionnaire. The expert group descriptions and feedback were recorded and used as the basis of the next version of the instrument. *In steps II and III*, data were analysed by SSPS (Statistical Package for Social Sciences), version 12.00. Reliability of the instrument was evaluated by means of internal consistency by calculating Cronbach's alpha coefficients and by item analysis. The internal consistency of the main categories and subcategories was assessed by calculating Cronbach alpha value in steps II and III. Item-to-total correlations were calculated for the various subcategories in nursing activities and nursing environment, and for the main category of nurse characteristics. The minimum recommended correlation between item and total scores is over .30 (Ferketich 1991, Nunnally & Bernstein 1994, Burns & Grove 2001) or .20 (Streiner & Norman 2003).

Validity of the instrument was evaluated by means of component analysis and content validity index. The Principal component analysis with varimax rotation was used to explore the structure of the instrument (Ferketich 1991, Rattray & Jones 2007). Principal component analysis KMO and Barlett's test have been reported to evaluate if correlation matrix is appropriate for principal component analysis. It was used to measure the level of congruence of empirical results with the main categories nursing activities and environment (Burns & Grove 2001, Rattray & Jones 2007). Content Validity Index for scale level has been calculated in data from nurses' evaluations of the instrument CCQH III in step III. A scale-level CVI of .80 or higher is acceptable (Polit & Beck 2004, Polit & Beck 2006). The consistency of children's replies was tested using by Gamma coefficients and Fisher's exact tests to evaluate negative dependence between two questions arguing in opposite directions (Paper III, V).

In the **third phase,** data were analysed by SSPS (Statistical Package for Social Sciences), version 12.00. First, the variables were characterised by descriptive statistics based on frequencies, percentages, means standard deviation and ranges. Sum variables were formed by summing up the coded responses and dividing the sum by the number of variables. The sum variables have the same scale as individual items in the original question from 1 to 3 or 1 to 4. The option "I have not been pain" and "I have not needed help" in the subcategory of physical care and treatment were excluded before the final calculations of means. For convenience, the Likert-scale responses "fully agree" and "somewhat agree" have been combined into one category, as have the options "fully disagree" and "somewhat disagree".

Power calculations were made with NQuery 4.0 Advisor. To get 0.5 differences of group means (SD 0.75 with groups), statistically significant at 0.01 levels with 90% probability, the sample size should be at least 312. The sample size (n=388) was large enough to use parametric tests without concerns of normality assumptions to reveal statistically significant associations between children's background variables and subcategories. Parametric tests have more power to reveal statistically significant differences or associations between groups and they should be used whenever possible (Burns & Grove 2001). T-test was used to compare the mean scores of sum variables with two categories. When a background variable had more than two categories, comparisons between groups were tested with one-way analysis of variance ANOVA, post hoc comparisons with Tukey HSD tests or Tamhane tests, depending on Levene's tests of equal variances. The level of statistical significance was set at $p<0.05$. (Paper III.)

Data from sentence completion were analysed by inductive content analysis (Paper IV). Prior to the analysis, the data were reviewed to gain an overview of the whole body of information. Although the children tended to respond with just one or two short sentences, these provided a rich insight into their experiences. The analysis was based on the method of inductive content analysis (Miles & Huberman 1994, Morse & Field 1995). The unit of analysis was a word or sentence that conveyed a clear meaning that was relevant to the question. In categorizing, issues denoting the same feature were grouped into the same category, and these groups were given titles to describe their contents. Finally, similar subcategories were grouped under more extensive broad main categories and the data were also quantified. (Paper IV.) The data analyses used in the study are summarized in Table 5.

Table 5. Designs, samples, methods of data collection and analysis of the study

Paper	Design	Samples	Methods of data collection	Type of analysis
I	Descriptive	Children (n=40, 4-11yrs)	Interviews	Content analysis
II	Descriptive	Children (n=35, 4-11 yrs)	Drawings	Content analysis
III	Descriptive	Children (n=388, 7-11 yrs)	CCQH III	Descriptive statistics, T-test, One-way analysis of variance, Tukey HSD tests/Tamhane tests, Cronbach's alpha coefficient
IV	Descriptive	Children (n=388, 7-11 yrs)	Sentence completion	Content analysis
V	Descriptive and explorative	Expert panel (n=7) Children (n=41, 7-11 yrs) Children (n=16, 8 -11 yrs) Children (n=8, 8-11 yrs) Children (n=388, 7-11 yrs) Nurses (n=19) Nurses (n=198)	CCQH 0 (66 items) CCQH I (60 items) CCQH II (59 items), Interviews CCQH III (58 items) Content validity testing questionnaire (Perälä 1995)	Descriptive statistics, Cronbach's alpha coefficient, Principal component analysis, Gamma coefficients, Fisher's exact tests, Content analysis

4.4 Ethical questions

The ethical aspects of scientific research were taken into consideration at all phases of the study (Burns & Grove 2001, ETENE 2001a, 2001b, 2001c, WMA 2002, Alderson 2004). The study focused on the quality of paediatric nursing care from children's perspective, which is an important subject especially since there are only a few studies made from children's perspective. However, when children are used as informants there are more ethical challenges during all phases of the study. The risks of emotional distress and possible benefits of the result must be assessed prior to conducting the study (Burns & Grove 2001, ETENE 2001b, Alderson 2004). However, there is always a possibility of risk and harm when the research area concerns hospitalization, which might give rise to emotional distress in children. However, in the future children could benefit from the improvement of the quality of paediatric nursing based on children's expectations and evaluations. In the following, a more detailed look is taken at the realization of research ethics in this study through the contents of approval of the research plan, information to the research subjects and staff and consent forms (ETENE 2001b, 2001c).

Approval of research in phases I and II was obtained in accordance with the research policy of each hospital, including permission from the Ethical Committee in Phase III/Phase II/step III. Research ethics was taken into consideration from the very beginning of the research process by drawing up as detailed a research plan as possible, in which ethically significant issues such as appropriateness of study theme, voluntary participation, data protection and resources needed in the study were carefully detailed (ETENE 2001b, 2001c).

In **Phase I**, the researcher attended a meeting of surgical ward nurses and a diabetes nurse to describe the purpose of the study and its practical implementation. Based on this, nurses working in the surgical ward and the diabetes nurse gave the parents of all children who met the inclusion criteria a cover letter and a consent form (Appendix 15) asking for consent for interviews. The cover letter included information about the aim of the study, approval obtained, addresses for correspondence and reporting of study results, destruction of interviews/drawings/questionnaires, making also clear that participation was voluntary and anonymous, and that withdrawal from the study was possible at any time. After this, the parents who had given consent for their child to take part in the study signed an informed consent. Parents whose children were at surgical ward gave it to nurses; at the same time, they agreed with the nurse on a time when the researcher could come and see them and conduct the interview. Parents whose children had insulin-dependent diabetes mellitus (IDDM) sent the consent form straight to the researher, who agreed on a time for the interview. Before the interviews, the researcher explained the purpose of the study using age-appropriate information to the children and asked them to give their informed assent orally. Assent is a term used in clinical research when minors (usually ages 8 to 18 years) are involved. Assent is the child's permission or affirmative agreement to participate in research. (Broome & Richards 1998, Lindeke et al. 2000, Beidler & Dickey 2001, ETENE 2001b, Rossi et al. 2003, Alderson 2004.*)* The age when a child is considered capable of written informed consent seemed to differ quite a lot: from older than seven years in international guidelines to age 15 years and over as required by Finnish law it (Act 488/1999, ETENE 2001b, Kankkunen et al. 2002).

In **Phase II and III**, the researcher attended a meeting for all wards taking part in the study to describe the aim of the study and its practical implementation; written instructions were drafted as well (Appendix 16). The informed consent process was similar to that in phase I. Nurses gave the parents of all children meeting the inclusion criteria a cover letter and a consent form (Appendix 17) asking for consent for study. After this, the parents who had given consent for their child to take part in the study signed an informed consent, after which verbal assent was obtained from the children. Seven parents refused to give permission for their child to participate. Eleven children refused to participate after their parents' consent. Thereafter, nurses gave the ”Child Care Quality at Hospital” questionnaire and coloured pencils for children. All questionnaires were returned in sealed envelopes to ward offices and the research contact nurses or head nurses returned them to the researcher. The children were given drawing or gel pens or stickers after the study. It can be discussed whether one should give a gift or not and if so, when (Neill 2005). The gift was a way of thanking the children for taking part in this study. The nurses were not asked for a written consent in advance; they decided on whether to respond on the basis of the cover letter that was received with the questionnaire (Appendix 10, 13). In phase II in pilot test II, the diabetes nurse informed the parents about the study by using the same forms and they returned their signed informed consent directly to the camp. The researcher requested verbal assent from the children attending the camp.

All the data in this study were collected and handled anonymously. The data were stored appropriately.

5 RESULTS

The results are presented in three parts according to research questions. The first part reports children's expectations concerning the quality of paediatric nursing care, which were the basis of the instrument development in study Phase II (Paper I, II). The second part describes how school-age children evaluated the quality of paediatric nursing care (Paper III, IV). It describes children's quality evaluations based on the Instrument "Child Care Quality at Hospital" CCQH III and children's experiences about the best and worst experiences during hospitalization collected by sentence completion. The third part describes the development of the "Child Care Quality at Hospital" Instrument and its final version (CCQH IV) based on psychometric testing (Paper V, summary).

5.1 Children's expectations concerning the quality of paediatric nursing care

In the first phase of the study, the children were asked to describe their expectations about nurses, nursing activities, environment in hospital and to draw an ideal hospital (Paper I, II). Because young children, especially those under school age, have a limited ability to understand abstract concepts (e.g. Piaget 1952, Docherty & Sandelowski 1999), interviews were always started by letting the children tell about their experiences of nurses, what the nurses had done with them and the nursing environment; only after that were the children asked to describe what kind of nurse they would expect to care for them, for example. The children had the opportunity to draw their ideal hospital either prior to, during or after the interview.

Children's expectations related to the nurse fell into three categories: the nurse's characteristics, the nurse's gender and colourful clothing. Of the nurse's personal characteristics, humanity was valued the highest, i.e. children expected the nurse to be "nice" and "kind" (Paper I). The people who appeared in the ideal hospital drawings were patients, parents, and nurses. All in all, only 12 drawings featured people. All the nurses were smiling and wore colourful uniforms. The nurses appearing in the boys' drawings were usually male; those in the girls' drawings were usually female. (Paper II.)

The children expected nursing activities from both nurses and parents. The nurse was expected by children to provide entertainment, including playing games with them, and to give patient education, explaining and informing them about matters related to their care. Nurses were also expected to provide activities involving caring, physical care and treatment, e.g. medication administration and other treatment procedures; and treat them with respect. The children also expected safety activities from the nurses, such as being present or at the bedside. (Paper I.) In drawings nurses were engaged in various physical nursing activities (Paper II).

As for the parents, what was particularly expected by the children was safety, entertainment and caring activities (Paper I), this was also seen in the few drawings (n=8) featuring parents in a drawing of an ideal hospital; they usually stood behind or round the child, i.e. as providing safety (Paper II).

The children had both social and physical expectations with regard to the nursing environment. The social expectations concerned parents as well as other children (friends/peers). According to the children, other children whether friends or other child patients on the ward, play a role in quality nursing. Other children were particularly important in relation to entertainment. (Paper I.) The patients who appeared in the ideal hospital drawings were usually resting or sitting, not doing anything; they were smiling and wore colourful clothes. However, in some drawings, the patients were playing. (Paper II.)

Children have many expectations related to the physical environment; their descriptions of the ideal hospital environment represented the hospital building, its surroundings and the patient rooms. Their drawn expectations regarding the hospital building and its environment concerned the appearance of the hospital, its courtyard and the weather (Paper II). Children expected entertainment to pass the time, pleasant rooms and privacy (later on this study in instrument privacy is under the social environment). Entertainment comprised objects, playgrounds with swings, animals and activities using the objects, like "playing and watching TV". The children wished to have not only toys but also animals, such as fish or a dog, in the hospital, as well as regular hospital furnishings and nursing instruments and food. (Paper I, II.) In children's expectations, privacy was part of quality nursing, although there were also children who wished for company or a shared room (Paper I).

5.2 Children's evaluations concerning the quality of paediatric nursing care in Finland

In this study, children's evaluations of the quality of paediatric nursing care were measured by the instrument "Child Care Quality at Hospital" developed in Phase II of the study. The results are presented according to the main quality categories of the instrument "Child Care Quality at Hospital" (CCQH III, Paper III) and the children's best and worst experiences during hospitalization (Paper IV). The main quality categories are nurse characteristics, nursing activities and nursing environment.

The highest ratings among the main categories were obtained for the nursing environment (mean=3.18, SD=0.44, please note: on a scale from 1 to 4), the second is nurse characteristics (mean=2.66, SD=0.236, on a scale from 1 to 3) and the last is nursing activities (mean=2.48, SD=0.290, on a scale from 1 to 3). Children rated nurse characteristics highly: the highest scores were recorded for the subcategories humanity and trustworthiness (mean=2.92, Table 6, Paper III.)

Table 6. Children's evaluations of nurse characteristics

	n	M	SD
NURSE CHARACTERISTICS (scale 1-3)	**388**	**2.66**	**0.236**
Humanity	**382**	**2.92**	**0.304**
Kind	387	2.91	0.283
Nice	381	2.88	0.334
Competence	**385**	**2.88**	**0.339**
Skilful	385	2.88	0.339
Sense of humour	**381**	**2.55**	**0.534**
Funny	381	2.55	0.534
Trustworthiness	**382**	**2.92**	**0.304**
Honest	382	2.92	0.304
Appearance	**375**	**1.82**	**0.781**
Colourful clothes	375	1.82	0.781

Children gave the best ratings for caring and communication activities (mean=2.74, SD=0.294); of individual items, children considered that the following were best realized: helps, listens and protects intimacy, all belonging to the subcategory caring and communication (Table 7). Children gave the lowest ratings to entertainment activities (mean=1.74, SD=0.469) and physical care and treatment (mean=2.47, SD=0.516). However, the differences were very small between the previous item and supporting initiative (mean=2.48, SD=0.480) and education (mean=2.49, SD=0.481) activities. (Table 7, Paper III.)

Table 7. Children's evaluations of nursing activities

	n	M	SD
NURSING ACTIVITIES (scale 1-3)	**385**	**2.48**	**0.290**
Entertainment	**380**	**1.74**	**0.469**
Talks about interesting things	378	2.12	0.622
Plays with children	377	1.36	0.548
Caring and communication	**379**	**2.74**	**0.294**
Helps	377	2.94	0.251
Listens	376	2.82	0.406
Protects intimacy	352	2.81	0.441
Considers child's opinions	377	2.71	0.470
Comforts	363	2.50	0.675
Encourages child to ask questions	373	2.30	0.717
Supporting initiative	**375**	**2.48**	**0.480**
Informs children of what they can do	371	2.69	0.554
Cares for child together with parents	372	2.51	0.695
Encourages participation in care	367	2.26	0.739
Education	**374**	**2.49**	**0.481**
Information that is easy to understand	371	2.67	0.506
Encourages asking questions	372	2.30	0.717
Physical care and treatment	**383**	**2.47**	**0.516**
Provides relief for pain	312	2.79	0.442
Takes account of child's food preferences	373	2.42	0.701
Helps with toileting	195	2.38	0.666
Helps with bathing	155	2.25	0.803
Helps with eating	106	1.85	0.790

Children also evaluated the amount of information that the nurses provided to them about: reason for hospitalization, treatment, medication, procedures, eating and drinking, moving in hospital, duration of hospitalization, home care instructions, going to school and leisure activities. Children had not received enough information about leisure activities (30%), going back to school (23%), home care instructions (16%), the duration of hospitalization (10%) and medication (10%) (Table 8). In the subcategory of physical care and treatment, many of the children opted for the response option “I have not needed help”, or concerning the pain management the option “I have not been pain”. A total of 17% had not been in pain while at hospital; and only 1% of the children felt they had not received enough pain medication. (Paper III.)

Table 8. Children’s evaluations about the amount of information received

	n	Enough information %	Some information %	Not enough information %
Education (scale 1-3)				
Eating and drinking	375	78	14	8
Treatment	376	72	21	7
Reason for hospitalization	376	71	23	6
Procedures	373	71	24	4
Moving in hospital	374	71	20	9
Medication	368	57	32	10
Duration of hospitalization	374	54	36	10
Going to school	362	54	23	23
Home care instructions	368	53	31	16
Leisure activities	361	42	28	30

The children gave the highest ratings to the physical environment (mean=3.26, SD=0.570). Among individual items, children considered that the following were best realized in nursing environment: parents provide company, it is easy to find different places and there are enough videos and games. The children were pleased with the company provided by parents and nurses, but dissatisfied with friends’ visits and company provided by other patients. The children had felt safe at hospital and gave high ratings to the emotional environment (mean=3.24). The children were least afraid of the nurses, doctors and being alone. They were most afraid of injections and pain. (Table 9, Paper III.)

By background variables, children’s age (p=0.001) and a scheduled admission procedure (p=0.019) influenced the amount of the information the children received. Children aged 11 thought that nurses gave them more information than did children aged 7, and those who were admitted for a scheduled procedure were more satisfied with the information they received than children admitted for emergency procedures. Children’s previous experiences of hospitalization (p=0.001) and the type of room the child was in (p=0.021) have associations with ratings about nurses’ entertainment activities. Children on surgical wards rated the nursing environment (p=0.017) and nurses’ caring and communication (p=0.028) more highly than children on paediatric wards. As a whole, the children evaluated their care as excellent when using school grades from 4 to 10. (Figure 2, Paper III.)

Table 9. Children’s evaluations of nursing environment

	n	M	SD	agree %	disagree %
NURSING ENVIRONMENT (scale 1-4)	**384**	**3.18**	**0.441**		
Physical	**384**	**3.26**	**0.570**		
Easy to find different places	379	3.71	0.675	93	7
Enough videos and games	379	3.58	0.807	88	12
Time has passed quickly	382	3.50	0.759	90	10
Enough books	380	3.42	0.890	85	15
Cosy and pleasant	380	3.12	0.979	76	24
Place to be with my parents	372	3.06	1.113	72	28
Enough toys	359	2.94	1.147	64	36
Enough crafts	359	2.75	1.233	61	39
Social	**382**	**3.03**	**0.620**		
Parents provide company	381	3.78	0.582	96	4
Nurses provide company	378	3.39	0.828	85	15
Privacy	378	3.24	1.033	78	22
Relatives can visit	347	2.93	1.226	65	35
Other child patients provide company	357	2.33	1.264	46	54
Friends can visit	326	2.23	1.310	40	60
Emotional	**379**	**3.23**	**0.629**		
Afraid of injections	375	2.32	1.181	43	57
Afraid of pain	375	2.25	1.138	41	59
Afraid of being alone	370	1.83	1.101	28	72
Afraid of doctors	371	1.23	0.649	6	94
Afraid of nurses	372	1.16	0.571	5	95

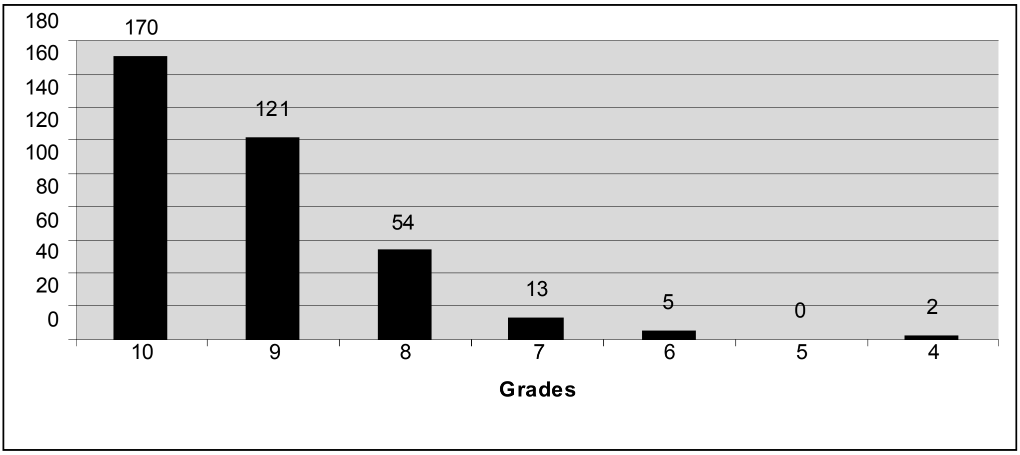

Figure 2. Children’s overall evaluations about their care at hospital with school grades

Children’s (n=362) best experiences during hospitalization fell into five main categories: people, people’s characteristics, activities, environment and outcomes. Children’s best experiences also gave a possibility to find connections, things being related to each other. The main category of people included the child as a patient, nurses, parents and family, friends and play workers and hospital clowns. To some of these people the children attached attributes connected with humanity and familiarity. The activities were related to the children themselves as patients and to nurses, parents and friends. The best single and most often mentioned experiences of activities during hospitalization were entertainment activities. Activities related to nurses were caring, entertainment, and physical care and treatment. Parents and family as well as the hospital and the children's own friends provided entertainment and safety activities. (Table 10, Paper IV.)

As regards the environment, children's best experiences consisted of entertainment objects and privacy. In a quantitative analysis, what children enjoyed most of all about their time in hospital were first, entertainment activities, and second, entertainment objects. Children also valued privacy during hospitalization as one of the best experiences about being in hospital. Some children thought that the best experience during their hospital stay was the outcome of care - getting better. This was related to being a patient, in which case the children also described as the best thing/outcome experiences related to being a patient, such as the possibility to rest and sleep and to be away from school. (Paper IV.)

Table 10. Children's best experiences during hospitalization and the connections between them (n=362)

			PEOPLE		
	Child as a patient	Nurses	Parents	Friends	Play workers / Clowns
CHARACTERISTICS					
Humanity		X		X	
Familiarity		X		X	
ACTIVITIES					
Caring	X	X			
Physical care and treatment		X			
Safety			X	X	
Entertainment	X	X	X	X	
ENVIRONMENT					
Entertainment Objects					
Privacy	X				
OUTCOMES					
Possibility to rest	X				
Getting better	X				
Being out of school	X				

Children's (n=353) worst experiences during hospitalization fell into four main categories: people, feelings, activities and environment. The focus was on the children's own experience of being a patient. As patients, children experienced feelings about symptoms of illness and separation in an environment where someone - who was not identified - performed physical care and treatment activities, especially procedures as well as food restrictions and waiting for procedures. As patients, the children felt symptoms of illness, mostly pain and separation from parents and family, friends, home and school. Hospitalization caused a disruption to usual routines such as school and contact with friends. The environment during hospitalization was one of the worst things, due to being bed-ridden, lack of activities and no privacy. (Table 11, Paper IV.)

Table 11. Children's worst experiences during hospitalization and the connections between them (n=353)

	CHILD AS A PATIENT
FEELINGS	
Symptoms of illness	X
Separation	X
ACTIVITIES	
Physical care and treatment	X
Procedures	X
Food restriction	X
Waiting for procedures	X
ENVIRONMENT	
Bed-ridden	
Lack of activities	
No privacy	

5.3 Development of the Quality Instrument "Child Care Quality at Hospital" (CCQH)

The development process of the "Child Care Quality at Hospital" Instrument was explained above under section 4.2. The starting point for instrument development was to design an instrument for children, based on children's expectations concerning the quality of paediatric nursing care. The instrument is based on qualitative data (Paper I, II), in which the main themes of interviews consisted of the three main categories selected from Leino-Kilpi's ”Good Nursing Care” instrument: nurse characteristics, nursing activities and nursing environment (Leino-Kilpi & Vuorenheimo 1992, 1994, Leino-Kilpi et al. 1994, 1999). In the development work, quality indicators used in earlier research were also utilized (Appendix 7, Paper V). The "Child Care Quality at Hospital" CCQH III has 58 items divided into three main quality categories: nurse characteristics (item numbers 10-20), nursing activities (item numbers 21-48) and nursing environment (item numbers 49-67) together with two sentence completion open-ended questions, children's overall evaluation about their care at hospital with a school grade from 4 to 10 and a drawing task with demographic variables (item numbers 1-9) (Appendix 12). In Phase II/step III, the purpose is develop further the”Child Care Quality at Hospital" Instrument based on material gathered from children (n=388) and the results of the instrument's content validity by nurses (n=198). The next chapters describe the psychometric evaluation of CCQH III (Paper V) and the fifth, not empirically tested version of the CCQH IV instrument based on the whole development process during this study. Methods used in evaluating the validity and reliability of the "Child Care Quality at Hospital" Instrument are presented in Table 12.

Table 12. Methods used in evaluating the validity and reliability of the “Child Care Quality at Hospital” Instrument

Purpose	Phase/ steps	Sample	CCQH	Method	Analysis	Parameters
REALIBILITY						
Internal Consistency	II/II	School-age children (n=41)	CCQH I	CCQH I	Item analysis	Cronbach α correlation Item-to-total correlations
	II/II	School-age children (n=16)	CCQH II	CCQH II	Item analysis	Cronbach α correlation Item-to-total correlations
	II/III	School-age children (n=388)	CCQH III	CCQH III	Item analysis	Cronbach α correlation Item-to-total correlations
Respondents' comments	II/II	School-age children (n=41)	CCQH I	Questions about comprehensibility and length of instrument CCQH I	Content analysis	Frequencies , %
	II/II	School-age children (n=16)	CCQH II	Questions about comprehensibility and length of instrument CCQH II	Content analysis	Frequencies, %
VALIDITY						
Content validity						
Expert analysis	II/I	Expert panel (n=7)	CCQH 0	Interview	Relevance, clarity and content of items	
	II/II	Nursing staff from 5 wards	CCQH I	Adapted version of the content validity testing questionnaire (Perälä 1995)	Relevance, clarity and content of items	Frequencies
	II/II	School-age children (n=18)	CCQH II	Interview	Relevance, clarity and content of items	
	II/III	Nursing staff (n=198)	CCQH III	Adapted version of the content validity testing questionnaire (Perälä 1995)	Relevance, clarity and content of items	Content Validity Index
Construct validity						
Factor analysis	II/III	School-age children (n=388)	CCQH III	CCQH III	Principal Component Analysis	Components Correlations

Reliability

In the main category of nurse characteristics, the consistency of children's replies was tested by using items describing opposite nurse characteristics in the same way as in the pilot tests (Phase II/step II). The results showed good consistency for the children's replies, indicating that they had been logical in their answers. Consequently, four opposite items and one negatively worded item were excluded from the final version. (Paper V.)

An alpha value of 0.80 is considered the lowest acceptable coefficient for a well-developed tool, while 0.70 is acceptable in the early stages of instrument development (Nunnally & Bernstein 1994, Knapp & Brown 1995). The low alpha values obtained in the pilot tests (Phase II/step II) may be due to small sample sizes, the use of a three-point Likert scale, and to the fact that some sum variables were based on only two items (Ferketich 1991, Knapp & Brown 1995). The alpha values showed a tendency to increase during the course of the instrument development for all the main categories: in nursing characteristics 0.383 (calculated only in step III), in nursing activities from 0.763 to 0.822, and in nursing environment to 0.548 to 0.761. The calculated alpha values in the main category nurse characteristics used only 6 positive items (kind, skilful, nice, funny, honest, colourful clothes), as the other items used were there opposites, and mainly included for testing the consistency of the children's replies. The alpha values were also calculated for CCQH IV, when three items from nursing activities and six items from the main category of nurse characteristics were removed (see also validity chapter, Table 13).

Table 13. Cronbach alpha values of the main and subcategories in different steps of Phase II

Main and subcategories	**Step II Pilot test I (n=41) CCQH I**		**Step II Pilot test II (n=16) CCQH II**		**Step III (n=388) CCQH III**		**CCQH IV**	
	Alpha values	No of items	Alpha values	No of items	Alpha values	No of items	Alpha values	No of items
Nurse characteristics [1]		12		11	0.383[2]	11	0.557	5
Humanity		6		5		5		2
Competence		0		1		1		1
Sense of humour		2		2		2		1
Trustworthiness		2		1		1		1
Appearance		2		2		2		0
Nursing activities	0.763	25	0.570	29	0.822	28	0.809	25
Entertainment	0.544	2	0.484	2	0.373	2		2
Caring and communication	0.619	6	0.607	6	0.656	6	0.647	5
Supporting initiative	0.352	3	0.524	3	0.541	3		3
Education	0.591	10	0.605	13	0.805	12	0.812	10
Physical care and treatment	0.636	4	0.664	5	0.565	5		5
Nursing environment	0.548	23	0.575	19	0.761	19		19
Physical	0.540	12	0.644	8	0.729	8		8
Social	0.234	6	0.274	6	0.570	6		6
Emotional	0.737	5	0.406	5	0.646	5		5

[1] calculated only in step III

[2] using only 6 positive items 6 (kind, skilful, nice, funny, honest, colourful clothes)

Item-to-total correlations were calculated for the various subcategories in nursing activities and environment, and for the main category of nurse characteristics. The minimum recommended correlation between item and total scores is over .30 (Ferketich 1991, Nunnally & Bernstein 1994, Burns & Grove 2001) or .20 (Streiner & Norman 2003). Item-to-total correlations ranged from 0.030 to 0.604 in the CCQH III. The lowest item-to-total correlations above .20 were obtained for the items “colourful clothes” (0.030), “takes account of child’s food preferences” (0.062) and “provides relief for pain” (0.179). The last two were not deleted from the new version of the CCQH IV, as they are crucial for their contents. Item-to-total correlations ranged from 0.062 to 0.611 in the CCQH IV. Exact values are described in Paper V. Still, there are some item-to total correlations that do not exceed .30. However, when deleting some items, in CCQH IV the item-to-total correlation improved in the main category of nurse characteristics and the subcategory education so that more items reached r > .30. However, especially the subcategory physical care and treatment remains problematic due to items concerning food preferences and pain management (Table 14).

Table 14. Item-to-total correlations in CCQH III and CCQH IV

CCQH III / CCQH IV MAIN CATEGORY/ Subcategories	n	Number of items	Item-to-total correlation	Acceptable items % r > .30	Acceptable items % r > .20
NURSE CHARACTERISTICS	362/374	6/5	0.030 - 0.351 / 0.255 - 0.464	33 % / 60 %	66 % / 100 %
NURSING ACTIVITIES					
Entertainment	375	2/2	0.231	0 %	100 %
Caring and Communication	337/339	6/5	0.218 - 0.543 / 0.209 - 0.545	83 % / 80 %	100 % / 100 %
Supporting initiative	360	3/3	0.292 - 0.446	66 %	100 %
Education	335/344	12/10	0.245 - 0.604 / 0.350 – 0.611	83 % / 100 %	100 % / 100 %
Physical care and treatment	77	5/5	0.062 - 0.487	60 %	60 %
NURSING ENVIRONMENT					
Physical	345	8	0.298 – 0.569	88 %	100 %
Social	314	6	0.210 – 0.431	50 %	100 %
Emotional	362	5	0.331 – 0.465	100 %	100 %

Validity

In Phase II/step III, nurses (n=198) working at paediatric wards were asked to judge the validity of the CCQH III by using adapted version of content validity testing questionnaires by (Perälä 1995). In step II, the same method was already used for the evaluation of the CCQH I instrument in connection with pilot I. The evaluation was done on a ward-by-ward basis. Nurses (n=19) had evaluated the instrument together, so there were answers from only 5 wards, which is why no statistical analyses could be performed. Nurses’ evaluations about the instrument were similar as in step III. The least relevant subcategories for the evaluation of the quality of care were those of appearance (.38) and sense of humour (.67). The clarity of the subcategories competence (.65), sense of humour (.68) and appearance (.74) was not very good, either. Nurses thought that the subcategory of appearance did not belong to the category of nurse characteristics (.69), whereas the level of agreement for all other subcategories was over .90. Level of agreement among nurses was over .95 for all subcategories measuring quality, except for appearance (.37), sense of humour (.69) and humanity (.93). In the nurses' assessments, the subcategories of humanity (.31), caring and communication (.31) and education (.31) showed the greatest overlap with other subcategories. (Paper V.) Besides, nurses evaluated whether the main categories measure the quality of paediatric nursing: activities 100%, nursing environment 95% and nurse characteristics 88%, and how subcategories cover the main categories (Table 15). Again, the most problematic one was the main quality category of nurse characteristics, and the clearest one was the category of nursing activities. Overall, the results provide a positive assessment of CCQH III. On the basis of the nurses' assessments, the items "colourful clothes", "helps", "information that is easy to understand" and "encourages child to ask questions" were deleted from the CCQH IV (see also reliability chapter). However, items such as sense of humour were left in the instruments, based on the results of the qualitative data. (Paper I, V.)

Table 15. Nurses' evaluation on whether the subcategories cover the main categories

MAIN CATEGORY (scale 1-4)	n	M	SD	Well %	Satisfactorily %	Poorly %	Not at all %
NURSING ACTIVITIES	186	3.83	0.378	83	17	-	-
NURSING ENVIRONMENT	188	3.73	0.523	76	21	2	1
NURSE CHARACTERISTICS	191	3.52	0.606	56	41	1	2

The construct validity of CCQH III was assessed using principal component analysis to measure the congruence of empirical results with the theoretical structure of the study with the main categories nursing activities and environment (Ferketich 1991, Rattray & Jones 2007). No principal component analysis was carried out for the main category of nurse characteristics owing to the use of opposite items and the number of subcategory items being small. The first principal component analysis was done with the main category of nursing activities including five theoretical subcategories, and the five principal components model explained 49.8% of the total variance analysis. Nine items loaded on the first component, which mainly included items from the subcategory caring and communication with the items "takes account of child's food preferences", and "provides relief for pain" from the subcategory of physical care and treatment. The second principal component consisted of eight items, all but one related to education. The third component consisted of items concerning discharge information included in the education subcategory. The fourth component included items helping with daily living, excluding items concerning food preferences and pain management. The last or fifth component included items from the subcategories entertainment and supporting initiative. The items with very weak loadings (under 0.40) were "information that is easy to understand" and "cares for child together with parents" (Appendix 18).

In Paper V the principal component analysis was done with deleted items ("colourful clothes", "helps", "information that is easy to understand" and "encourages child to ask questions"). After that, seven items loaded on the first component, which included items from the education subcategory dealing specifically with information needed by children at hospital together with the item "cares together with parents". The second principal component consisted of all items related to the caring and communication subcategory and the last two items ("takes account of child's food preferences", and "provides relief for pain") were included in the subcategory physical care and treatment. This subcategory was the fourth component including items helping with daily living excluding the previous items. The third component consisted of items concerning discharge information. The fifth component consisted of the items from the subcategories entertainment and supporting initiative. Items with very weak loadings (under 0.40) were "provides relief for pain" and "cares together with parents". (Paper V.) The main category of nursing environment included three subcategories, and the three components model explained 49.8% of the variance. An item with very weak loading (under 0.40) was "other child patients provide company." (Paper V.)

The tests of construct validity provide support for the theoretical construct behind the CCQH. The main category nurse characteristics was included in the final instrument CCQH IV, based on children's expectations (Paper I, II) and partly because it is part of the "Good Nursing Care" instrument (Leino-Kilpi & Vuorenheimo 1992, 1994, Leino-Kilpi et al. 1994, 1999) and nurse characteristic have been used as quality indicators in previous literature (see Appendix 7). However, six items from the main category of nurse characteristics were deleted, mainly negative, opposite items (Paper V). In nursing activities the main category caring and communication activities loaded on the same factor, as did education activities with two different factors, based on content, education activities during hospitalization and discharge information. The subcategory physical care and treatment with daily helping is clear, whereas especially items related to pain management and food preferences are problematic. In the future, entertainment and supporting initiative could perhaps be placed under the same subcategory. Three items were deleted from the main category of nursing activities. No changes were made to the main category of nursing environment. The instrument should be tested more in clinical practice to see whether the construct will change further. The content based especially on the tested items, the results of children's best and worst experiences during hospitalization like outcomes are not included in this version.

Appendix 19 presents the "Child Care Quality at Hospital" CCQH IV, the fifth version of the instrument which has not yet been tested with children. The content of the main and subcategories of the CCQH IV is shown in Table 16.

Table 16. Content of the “Child Care Quality at Hospital” CCQH IV

The “Child Care Quality at Hospital” CCQH IV 53 (49 items + 3 open + drawing)		
NURSE CHARACTERISTICS 5	**NURSING ACTIVITIES 25**	**NURSING ENVIRONMENT 19**
Items (5)	**Items (25)**	**Items (19)**
Humanity (2)	**Entertainment (2)**	**Physical (8)**
Kind	Plays with children	Time passes quickly
Nice	Talks about interesting things	Enough books + papers
Competence (1)	**Caring and communication (5)**	Enough videos and games
Skilful	Protects intimacy	Enough crafts
Sense of humour (1)	Listens	Enough toys
Funny	Considers child’s opinions	Place to talk and play with my parents and guests
Trustworthiness (1)	Encourages child	Cosy and pleasant
Honest	Comforts	Easy to find different places
	Supporting initiative (3)	**Social (6)**
	Informs children what they can do	Privacy
	Encourages participation in care	Parents provide company
	Cares for child together with parents	Relatives can visit
	Physical care and treatment (5)	Friends can visit
	Takes account of child’s food preferences	Nurses provide company
	Provides relief for pain	Other child patients provide company
	Helps with eating	**Emotional (5)**
	Helps with bathing	Afraid of being alone
	Helps with toileting	Afraid of injections
	Education (10)	Afraid of nurses
	Reason for hospitalization	Afraid of doctors
	Treatment	Afraid of pain
	Medication	
	Procedures	
	Eating and drinking	
	Moving in hospital	
	Duration of hospitalization	
	Home care instructions	
	Going to school	
	Leisure activities	

6 DISCUSSION

The purpose of this study was to describe children's expectations and evaluations concerning the quality of paediatric nursing care and to develop a quality instrument for hospitalized school-age children. To achieve this, the research process had the following three purposes: First, to explore children's expectations concerning the quality of paediatric nursing care. Second, to develop an instrument for evaluating the quality of paediatric nursing care from children's perspective based on their expectations and explore the psychometrics of the instrument. Third, to evaluate the quality of paediatric nursing care as perceived by children aged 7-11 in Finland. This section discusses the validity and reliability of the study and its main findings in relation to previous literature. The last part consists of conclusions and suggestions for further research.

6.1 Validity and reliability in the different study phases

Validity and reliability are the most important criteria in assessing the quality of a study. Validity is a measure of the truth and accuracy of a study in relation to the phenomenon of interest, while reliability represents the consistency of the measurement. Although validity can never be fully and exhaustively proven, it is always possible to support the extent to which the research measures what it is intended to measure. Validity, like reliability, is a matter of degree, and it can vary from one sample to another. (Polit & Hungler 1999, Burns & Grove 2001, Polit & Beck 2004.)

The data were collected from children aged between 4-11 years in Phase I and children between 7-11 years in Phases II and III. The age range of children was wide in this study. The cognitive, linguistic, social and emotional maturity as well as motor skills of children under school age (2-6 years) are different from those of school-age children (e.g. Piaget 1952, Selman 1980, Faux et al. 1988, Deatrick & Faux 1991, Scott 2001, de Leeuw et al. 2004, Nurmi et al. 2006). According to Piaget (1952), their cognitive development is at the preoperational stage, and they think in a very concrete and self-centred way. The meanings of words can be broader or narrower than in the language of adults. A child usually responds to questions in a precise, but one-dimensional manner. (Piaget 1952, Koppinen 1989, Deatrick & Faux 1991, Kortesluoma et al. 2003.) At the stage of concrete operations, children (7-11 years) can produce more information about their experience than younger ones because of their increased cognitive, linguistic, social, and emotional maturity and positive relationship with an adult (e.g. Piaget 1952, Selman 1980, Faux et al. 1988, Koppinen 1989, Deatrix & Faux 1991, Scott 2001, de Leeuw et al. 2004, Nurmi et al. 2006). Language skills are further developed and reading skills are acquired. Children begin to learn about classifications and temporal relations, but they still have problems with logical forms, such as negations. They become much more capable of perceiving underlying reality. (de Leeuw et al. 2004.) Cognitive abilities are characterized by children's ability to mentally represent their perceptions and to view themselves and their actions objectively (Piaget 1952, Deatrick & Faux 1991). In the next chapters, the validity and reliability of the study in different study phases is discussed, taking also into account also the age and developmental stage of the children.

6.1.1 Validity and reliability of Phase I

In next paragraphs, validity and reliability in the first study phase will be discussed. In this phase, data were collected by interviews (Paper I) and drawings (Paper II). In this discussion, discussion about sentence completion (Paper IV) in Phase III is also included, due to the similar nature of the data. The validity and reliability are examined through the concept of trustworthiness, which encompasses the dimensions of credibility, transferability, confirmability and dependability (Lincoln & Guba 1985, Miles & Huberman 1994, Polit & Hungler 1999, Polit & Beck 2004).

Credibility (parallel to internal validity) refers to confidence in the truth of the data. It depends on the researcher's ability to create confidence in the accuracy of the data. (Miles & Huberman 1994, Polit & Hungler 1999, Polit & Beck 2004.) The credibility of the interview themes, instructions given to children for drawings and sentence completion was tested in a pilot sample (n=8) prior to the study. Some concepts - such as quality - can be too difficult for children to understand. Thus, before actual data collection, the concept "good" was used instead of "quality" and the term "ideal" hospital in the instructions for drawings.

To ensure the credibility of the data, the researcher conducted all the interviews herself, reserving sufficient time in order to create trust with the children. Meeting the children more than once would have increased credibility and reliability, as the interviewer would have become more acquainted with each child's ability and means of expressing themselves (see Deatrick & Faux 1991). Unfortunately, this was not possible. However, before the actual interviews, the researcher familiarized herself with the children by talking or playing with them, or the children had an opportunity to start by drawing an ideal hospital. Drawing pictures at the beginning of an interview can alleviate anxiety (Faux et al. 1988, Coyne 1998, Kortesluoma et al. 2003). In the interviews conducted at the children's homes (n= 9), the researcher felt that she had better opportunities to make herself familiar with the child than in hospital (n=31). Less formal, more familiar settings may help the child view the researcher as an interested adult rather than an authority (Faux et al. 1988). Because young children have a limited ability to understand abstract concepts, follow-up questions focusing on concrete facts and recent events were necessary, and the children were free to tell their own stories and use action words (e.g. Faux et al. 1988, Docherty & Sandelowski 1999, Kortesluoma et al. 2003) to improve the credibility of the data. The credibility of the results is increased by the researcher's experience in paediatric nursing.

To attain a comprehensive understanding of a phenomenon, multiple data sources or multiple methods can be used to address the research problem (Lincoln & Guba 1985). Especially credibility can be improved by the use of multimethods with children (Faux et al. 1988). There can always be a gap between what is understood and what is asked in the world of a child. Thus, the use of multimethods, including qualitative strategies, can enrich understanding (Deatrick & Faux 1991, Scott 2001). In this study phase, credibility was confirmed by using data and method triangulation (Paper I, II). Several authors (e.g. Krahn 1985, Poster 1989, Deatrix & Faux 1991, Bellack & Fleming 1996, Wesson & Salmon 2001, Barker & Weller 2003, Driessnack 2005) have suggested that an appropriate way to collect information about children's perceptions and experiences is by means of projective techniques, such as drawings, especially with children under school age. However, the problem is the credibility of the drawings. The primary limitation of this study is the subjective component involved in the drawings, which creates a practically uncontrollable variable (DiLeo 1983). For improving control, standardized instructions were used and the children had to describe and explain their drawings for verification. Data collection was as objective as possible, and the analysis was restricted to the specific clearly observable items in the drawings, and no attempt to interpret the drawings as a whole was made. A further limitation is that the children made only one drawing for this study: it is recommended that children's drawings should be assessed over time, using more than one drawing (DiLeo 1983, Scavnicky-Mylant 1986). However, when using drawings together with interviews several advantages can be identified: data collection is non-directive, non-threatening, requires no simple "correct" answers, and helps identify feelings and desires that subjects may not be consciously aware of or able to express verbally (e.g. Lynn 1986, Faux et al. 1988, Poster 1989, Driessnack 2005).

An important criterion in credibility is respondents' personal experience of the issue under the study (Lincoln & Guba 1985). The objective was to obtain a comprehensive view of health care expectations in children of different ages hospitalized for a variety of reasons. Half of the children who were interviewed and produced drawings had insulin-dependent diabetes mellitus (IDDM); these diabetic children visit the hospital for follow-ups on a regular basis (Rytkönen et al. 2001) and they have a lot of experience of hospitals. The other half of the children came from surgical wards, hospitalized mainly for acute health problems. To be eligible for the study, at least one overnight stay at hospital was required. Thus, all the children in the data had experiences about hospitalization, and they were able to describe their expectations concerning nurses, nursing activities and environment. The focus of the study was on nursing care. It is, however, difficult for children to distinguish between nursing activities and the activities of physicians. It is rather obvious that part of the children's responses had to do with physicians, even though nursing was emphasized and the whole time of hospitalization was under consideration. The wide age range (4-11 years) also had an impact: the ability of younger children to describe their expectations and as well as to draw was clearly different compared to older children (e.g. Piaget 1952, Deatrick & Faux 1991). Older children's interviews and drawings procedured richer data. However, the basic elements were the same, and this provides a basis for presenting the results together. The credibility of the interview data may be impaired by the shortness of the interviews. Letting the participants read and comment on the results would also had increased the credibility of the results

(Miles & Hubermann 1994), but due to their age, it was not feasible. On the other hand, parents could have evaluated the credibility of the results together with their children. In sentence completion in Phase III, in some questionnaires the children's responses were written by their parents. In most of them, however, it was clear that children had written the responses by themselves – this could be seen based on the spelling and grammatical errors in the responses. However, it is not clear how much the parents responded from their own perspective and what their influence was on children's responses.

Transferability (parallel to external validity) refers to the extent in which the findings can be transferred to other topics and contexts (Lincoln & Guba 1985, Miles & Hubermann 1994, Polit & Beck 2004). In the first phase of this study, data were collected from one university hospital. Respondents were recruited for the study in the outpatient clinic by a diabetes nurse and at surgical wards by nurses. In the instructions for nurse, it was emphasized that all children fulfilling the inclusion criteria should have the opportunity to participate in the study. Nurses may, however, have used unconscious criteria for selecting the respondents (for example, they may have selected more active and motivated children). In the first phase, there are more boys (70%) than girls in the data; the boys mainly came from the surgical ward. Sample size can be estimated to be adequate because the saturation point was reached. According to Lincoln and Guba (1985), the researcher's task is not only to transfer the findings but to provide data that makes transferability judgements possible for potential users of the results of the study. In this study, the intention was not to make generalizations about children's expectations but to use the results in developing an instrument based on children's own expectations about the quality indicators in paediatric nursing care.

The circumstances in which the study is conducted may influence its validity and thereby the transferability of the findings (Burns & Grove 2001). The interviews with children with diabetes were carried out in the outpatient clinic (n=11) of the hospital or in their homes (n=9); other children on the surgical ward were interviewed either in patient rooms (n=5) or in the examination room (n=15), allowing the parents to be present if they or their child so wished. The parents were present in some interviews. The parents' presence was assumed to help the child respond freely and increase the child's trust in the interviewer. During the interviews, the parents were not allowed to interfere with the child's answers, which would have severely affected the reliability of the results.

Confirmability (parallel to objectivity) refers to the objectivity or neutrality of data, and involves the usefulness of the results; the results also need to be based on the data, not only on the researcher's conceptions (Lincoln & Guba 1985, Polit & Beck 2004). In this study, the children did not know the researcher personally, which facilitated a professional distance from their experiences. On the other hand, familiarity of the researcher could have improved each child's ability and means of expressing themselves. Furthermore, the drawings were not interpreted and a researcher wrote up what the children drew and in what order. An attempt has been made to increase the reliability of empirical data by providing direct quotes/drawings to support the analysis (Paper I, II). In Phase

III, to establish confirmability, the children's own words were used to substantiate the interpretations of the data. Some children had answered very briefly using single words. However, the analysis focused only on the explicit content of the words; the writings were not interpreted. Nonetheless, many of the children's answers were very concrete and provided clear statements of their best and worst experiences. (Paper IV.)

Dependability (parallel to reliability) refers to the stability of the data over time and over conditions (Polit & Beck 2004). Dependability is closely associated with confirmability (Lincoln & Guba 1985, Polit & Hungler 1999.) One criterion is the auditability of the results, which means that other researchers must be able to repeat the study by following the same process. The aim was to analyse data carefully to make sure that the voice of the children was properly represented by classification of transcribed data, but also by going back to the raw interviews and drawings several times during the data analysis. To ensure the auditability of this study, each stage of the research process is clearly described, explaining and justifying what was done and why. However, interpretations by a researcher are always personal, which is why the use of a second categorizer might have increased the dependability of the study (Polit & Hungler 1999). However, an attempt was made to increase reliability in the following manner: when the researcher did the analysis, it was discussed and reviewed with a group of doctoral students (see Polit & Hungler 1997). Administration as well as environmental factors during the interview, e.g. noise in patient rooms, may have affected some children's ability to concentrate, and thereby the credibility and reliability of the results. However, nearly all interviews were made in a quiet environment without any disturbing factors. Personal factors, such as fatigue, may also have affected the accuracy of data, particularly in young children whose attention span is relatively short. (Deatrick & Faux 1991.)

6.1.2 Validity and reliability of Phase II

In this section, the validity and reliability in study Phase II is discussed. The emphasis is, however, on the "Child Care Quality at Hospital" instrument, which is also connected to Phase III. Validity of the instrument refers to the degree to which the instrument measures what it is supposed to be measuring. Validity has different aspects and its assessment can be approached from many angles, such as content, construct and external validity (Polit & Hungler 1999, Burns & Grove 2001, Polit & Beck 2004). In this study, the quality instrument "Child Care Quality at Hospital" for school-age children was developed (Phase II). The CCQH was evaluated for its content and construct validity as well as internal consistency in different phases of the study (Table 12, chapter 5.3).

Content validity is used to evaluate the operationalization of the concepts; it also refers to the degree to which an instrument has an appropriate sample of items for the construct being measured. Designing a new instrument begins with through conceptualization of the construct so that the instrument can capture the entire content domain. (Ferketich 1991, Polit & Hungler 1999, Burns & Grove 2001, Polit & Beck 2004, Polit & Beck 2006, Rattray & Jones 2007.) In this study, the instrument, CCQH, was mainly based on data from Phase I (Paper I, II), previous literature (summary, Appendix 7) and Leino-Kilpi's "Good Nursing Care" quality categories: nurse characteristics, nursing activities and environment (Leino-Kilpi & Vuorenheimo 1992, 1994, Leino-Kilpi et al. 1994, 1999). The results of Phase I was most influential for the instrument construction. The main problem, however, is the concept quality itself, because many earlier studies on the quality of care have had difficulties arising from the limited theoretical underpinnings of concepts (e.g. Thomas & Bond 1996, Attree 2001, Currie et al. 2005) and especially lack of studies from children's own perspective.

The content validity of the CCQH was evaluated by using expert analysis four times (Table 12). A panel of experts (n=7) was used to evaluate the relevance, clarity and content of the items of the first version of the CCQH 0. The children themselves were also used in Phase II/step II. Several authors (Hockenberry-Eaton et al. 1998, de Leeuw al. 2004, Stewart et al. 2005) reported using a focus group made up of children to evaluate the instrument's undergoing development or revisions. Using more children in the evaluation of the content of the instrument could have improved the instrument and made it more children-centred. The selection of the items for the final version of the CCQH IV was based upon evaluations among the nurses (n=198) working at paediatric wards. However, in the final version there are quality indicators such as sense of humour. (Paper V.) Thus, there is evidence supporting face validity as well as content validity of CCQH IV. The CCQH was aimed to be a general quality instrument for school-age children in inpatient hospital settings. Therefore some alterations need to be made in the case of using it in outpatient settings. Most of the items are also relevant for outpatient care, such as those concerning information.

Construct validity indicates the fit between the conceptual definitions and operational definitions of variables (Polit & Hungler 1999, Burns & Grove 2001, Polit & Beck 2004, Rattray & Jones 2007). Polit & Hungler (1999) have stated that the more abstract the concept, the more difficult it is to achieve an acceptable level of construct validity. The construct validity of this study was evaluated by using Principal Components Analysis (PCA). The theoretical framework underlying the CCQH was mainly supported by the results of the principal component analysis. The construct of the instrument seems to be clear, and the instrument provides a general measure of quality for use at paediatric wards. However, the component analysis indicated that there is still a need to test the positioning of some items. There are similar results from other studies using instruments based on Leino-Kilpi's "Good Nursing Care" Scale (Rehnström et al. 2003, Kalam-Salminen 2005, Ruotsalainen 2006), even though the psychometrics of the Scale has been stated to be valid for measuring the quality of hospital care (Leino-Kilpi et al. 1994, Wasenius 2000, Leinonen 2002, Rehnström et al. 2003) and the theoretical structure of the instrument has been tested also earlier with school-age children (Pelander & Leino-Kilpi 1993). Consequently, further testing is needed to develop the theoretical structure of the instrument.

Reliability is defined as the degree of consistency or accuracy with which an instrument measures the attribute it is designed to measure. The reliability of an instrument can be assessed from the aspects of stability, equivalence and internal consistency. (Nunnally & Bernstein 1994, Polit & Hungler 1999, Burns & Grove 2001, Streiner & Norman 2003, Polit & Beck 2004, Rattray & Jones 2007.) In this study, the reliability of the CCQH instrument was evaluated by means of internal consistency by calculating the Cronbach's alpha coefficients, by item analysis and based on the comments of respondents (Table 12, Paper III, V). The alpha values of the main category of nurse characteristics varied between 0.383-0.557, in nursing activities between 0.570-0.822, and in nursing environment between 0.548-0.761 (Table 13). The main category of nurse characteristics was the most problematic. Items not showing high correlations may be deleted from the instrument (Ferketich 1991, Nunnally & Bernstein 1994, Rattray & Jones 2007). However, according to Streiner and Norman (2003), all decisions concerning the omission or addition of items must be well argued from the point of view of the theoretical framework. The items presented in the CCQH were based on the children's expectations, and some items were left in the instrument, even though the item correlations were not so high. Exact item-to-total correlation is described in Paper V.

6.1.3 Validity and reliability of Phase III

In this chapter, the validity and reliability related to the research process and external validity of Phase III will be described. The "Child Care Quality at Hospital" instrument CCQH III (reliability and validity of the instrument, see chapter 6.1.2) was used in Phase III to collect data from school-age children in Finland (Paper III, IV). Part of the instrument, validity and reliability related to sentence completions (Paper IV), has already been discussed in chapter 6.1.1.

External validity refers to representative sample size and generalizability of the results (Burns & Grove 2001, Polit & Beck 2004). A sampling plan with inclusion criteria was developed to increase the representativeness of the sample and to decrease systematic bias and sampling error, all contributing to validity (Polit & Hungler 1999). In order to get reliable results, this study attempted to gather a representative sample size from hospitalized school-age children. Power analysis was used to determine the representative sample. The data were collected on the paediatric clinics of Finland's five university hospitals with the exclusion of intensive care, psychiatric, neurological and outpatient wards for paediatric patients. A total of 23 medical and surgical wards for school-age children were included in the data. (Paper III, IV.)

For defining the numbers of respondents in the wards, statistics of children in the wards during a month was asked. The national statistics of Stakes (2003) were useful as well. The data were collected in proportion to the number of children admitted to each ward, based on the statistics of the previous year. The sample was representative of school-age patients in Finland, and the response rate was fairly high (91%). The results can be generalized to school-age children across Finland. Drop-out analysis was attempted in the wards, but it varied a lot and the results of drop-out are not necessary trustworthy. Based on statistics given by ward heads, 183 children fulfilling the inclusion criteria were omitted and 64% children cared in the wards were reached. The result, however, is not quite trustworthy, due to differences in statistics. Some children were excluded because they were in hospital for such a short time and it was difficult to get in touch with parents to get their informed consent. Thus, no conclusions can be made about those who failed to respond as their background variables are not known. From the point of view of results, it might be significant to know who did not answer the instrument and whether their opinions differed from those of respondents.

There are a number of potential sources of *random error in the measurement process*, such as situational contaminants, transitory personal factors, response-set biases, administration variations, instrument clarity and format (Polit & Hungler 1999, Polit & Beck 2004). Children responded to the instrument during the discharge process. However, the circumstances where and when children completed the questionnaire are not known. The children usually had all morning to prepare for the discharge from hospital and had time to respond; however, the researcher had no knowledge of how eager the children were to get home and how this may have affected their answers. On the other hand, the distribution of questionnaires in a clinical setting is an efficient way to collect data (Polit & Beck 2004). The researcher visited each ward personally and informed the staff in the same way about the process of the study, and a contact person had been appointed on each ward to take responsibility of the study.

Parents' presence during completion of the questionnaire could have affected the answers, especially those of the youngest children. Based on the results, younger children needed more help with filling in the questionnaire ($p<0.001$); the younger the child, the more help they needed with reading ($p<0.001$), understanding the questions ($p<0.001$) and writing their answers ($p<0.001$). (Paper III.)

The reliability of measurements and the motivation of respondents to participate in a survey depend crucially on the comprehensibility and length of the instrument (Burns & Grove 2001). The instrument CCQH III consisted of 58 items, which may have been too long for some children because there were more missing answers towards the end of the questionnaire than at the beginning. The question still remains whether the instrument is *sensitive* enough to be used with heterogeneous groups of children who have a wide range of medical conditions from fractures to leukaemia. Part of the reason for missing data in some items (e.g. "other patients provide company") may lie in the particular diseases suffered by children or in nursing decisions to isolate patients. During the planning period of the instrument, response-set, instrument clarity and suitability of the format for children were under consideration: there are no negatively formulated items in the "Child Care Quality at Hospital" instrument (Rifkin et al. 1988), the number of response options is limited to three and four and they are also represented graphically (Holaday & Turner-Henson 1989, Rebok et al. 2001, Scott 2001, Borgers et al. 2004, de Leeuw 2004), there are pictures and colourful pages, and questions were planned so as to have relevance for the children's own experiences (Holaday & Turner-Henson 1989, Scott 2001).

6.2 Discussion of the results

Next, the results of this study are discussed and compared with previous literature in accordance with the research questions. First, children's expectations about the quality of paediatric nursing care will be discussed. Second, children's evaluations of the quality of paediatric care in Finland are described. In the literature search, there were no studies analysing only the expectations of children, but the studies used many different concepts (experiences, views, perceptions, satisfaction and voices). Thus, in the discussion about the results of children's expectations and evaluations, studies made from children's perspective as well as those done from parents' point of view about the quality of paediatric care have been used (chapters 2.2.1 and 2.2.2). These are followed by a discussion about the Quality Instrument "Child Care Quality at Hospital" (CCQH).

6.2.1 Children's expectations concerning the quality of paediatric nursing care

This study set out to describe children's expectations concerning the quality of nursing care (Paper I, II). These could be divided into those related to the nurse, to nursing activities and to the nursing environment (Paper I). The emphasis on physical elements in the drawings may have had to do with the research method and the assignment given to the children (Paper II).

The characteristics expected from the nurse were humanity, a sense of humour and reliability (Paper I). The results were consistent with those obtained in previous studies (e.g. Rifkin et al. 1988, Simonian et al. 1993, Davis 1995, Schaffer et al. 2000, Sartain et al. 2001, Magaret et al. 2002, Battrick & Glasper 2004, Chesney et al. 2005, Coyne 2006b, Lindeke et al. 2006, Shaw et al. 2006a, 2006b). In this study, children, especially boys, also had expectations about nurses' gender. However, in this study the children made no mention about expectations concerning nurses' competency, which has been one of the quality indicators in earlier studies (Budreau & Chase 1994, Brown et al. 1995, Davis 1995, Callery & Luker 1996, Thornton 1996, Homer et al. 1999, Marino & Marino 2000, Schaffer et al. 2000, Filani 2001, Shields & King 2001, Ygge & Arnetz 2001, Bragadóttir & Reed 2002, Contro et al. 2002, Cygan et al. 2002, Stratton 2004, Ygge & Arnetz 2004, Haines & Childs 2005, Micheli & Clark 2005, Schmidt et al. 2007) made mainly from parents' perspective.

In this study, children expected nursing activities from both nurses and parents. From nurses, they expected entertainment, education, caring, physical care and treatment, respect and safety activities. In previous studies, made from the perspective of children and parents (see Appendix 7), all others have been mentioned many times, but entertainment activities in only two studies (Chesney et al. 2005, Schmidt et al. 2007). Earlier studies (e.g. Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Sartain et al. 2001, Shields & King 2001, Ygge & Arnetz 2001, Bragadóttir & Reed 2002, Cygan et al. 2002, Magaret et al. 2002, Carney et al. 2003, Co et al. 2003, Battrick & Glasper 2004, Lawoko & Soares 2004, Stratton 2004, Ygge & Arnetz 2004, Aitken & Wiltshire 2005, Ammentorp et al. 2005, Chesney et al. 2005, Haines & Childs 2005, Heller & Solomon 2005, Micheli & Clark 2005, Witchell & Lester 2005, Ammentorp et al. 2006, Lindeke et al. 2006, Mah et al. 2006, Schmidt et al. 2007) have identified especially patient education and information as a critical quality indicator. Entertainment and education activities are important in the role of supporting children's right to receive information in accordance with their level of development (United Nations 1989, Decree on Enforcement of the Convention on the Rights of the Child 1130/1991, Act 785/1992). Two of the articles of the European Association for Children in Hospital (EACH 1988) emphasize child's right to information and participation in accordance with age and maturity as well as children's full opportunity for play, recreation and education during hospital period. Appropriate counselling and guidance may reduce children's fears as well as increase their feeling of safety and trust in nurses. Regardless of parental presence, children look to nurses for reassurance and comfort (also e.g. Marino & Marino 2000, McPherson et al. 2000, Varni et al. 2000, Magaret et al. 2002, Stratton 2004, Ammentorp et al. 2005, 2006, Schmidt et al. 2007). Children expectations concerning nurses' possibility to play with them may not be altogether realistic due to the tight schedules and lack of time in the wards, but nurses should see entertainment activities, such as play, as basic needs of children and attempt to fulfil their expectations.

The children expected safety, entertainment and caring activities from their parents as well (Paper I). Safety activities were also seen in some drawings; the parents typically appeared around or beside the child (Paper II). Parents' participation in care is an important quality indicator in paediatric nursing care, especially from the parents' viewpoint (Kvist et al. 1991, Price 1993, Budreau & Chase 1994, Brown et al. 1995, Enskär et al. 1997, Marino & Ganser 1997, Homer et al. 1999, Stubblefield & Murray 1999, Marino & Marino 2000, Varni et al. 2000, Ygge & Arnetz 2001, Bragadóttir & Reed 2002, Cygan et al. 2002, Co et al. 2003, Stratton 2004, Ygge & Arnetz 2004, Ammentorp et al. 2005, Haines & Childs 2005, Micheli & Clark 2005, Witchell & Lester 2005, Ammentorp et al. 2006, Pritchard & Howard 2006, Shaw et al. 2006a, 2006b). Family-centred care has been recognized as a basic tenet of paediatric nursing, because children are believed to benefit from their parents' continuous presence (Coyne 1996, Power & Franck 2008). However, Migone et al. (2008) found that less than two thirds of children (n=50) saw their parents as much as they wanted. Also Shields et al. (2004) found that parents' rights to stay with their children in hospital were not being fully met. Hallström et al. (2002b) found in their observational study that the most prominent parental needs during a child's hospitalization were the needs for security and mediating security to the child.

Some children in hospital setting saw other child patients one element of the social environment as increasing the quality of nursing care (Paper I). This is obvious for school-age children, with increasing orientation towards the world outside the home and with friends/peers becoming more important (Deatrick & Faux 1991, Nurmi et al. 2006). Only in some previous studies (Sartain et al. 2001, Carney et al. 2003, Battrick & Glasper 2004, Shaw et al. 2006a, 2006b), friends or other paediatric patients have been seen an important part of the quality of nursing care. One reason for this may be the fact that earlier studies were made mainly from the perspective of parents, who do not emphasize this indicator as being important. There has been little research on peers' role in paediatric care especially in acute care, as regards to such effects as their impact on a child's coping or satisfaction with care.

In this study, children expected entertainment facilities in the hospital, pleasant and comfortable patient rooms and opportunity to privacy (Paper I); expectations concerning entertainment facilities were especially seen in drawings (Paper II). The importance of hospital environment has also been recognized in previous studies (e.g. McPherson et al. 2000, Schaffer et al. 2000, Filani 2001, Sartain et al. 2001, Bragadóttir & Reed 2002, Cygan et al. 2002, Carney et al. 2003, Battrick & Glasper 2004, Curtis et al. 2004, Aitken & Wiltshire 2005, Ammentorp et al. 2005, Chesney et al. 2005, Haines & Childs 2005, Micheli & Clark 2005, Witchell & Lester 2005, Ammentorp et al. 2006, Lindeke et al. 2006, Mah et al. 2006, Pritchard & Howard 2006, Shaw et al. 2006a, 2006b, Schmidt et al. 2007) as an essential part of the quality of paediatric nursing. The children's drawings of the patient room clearly highlighted the importance of entertainment and activities, the lack of which is a major stressor in children's hospitalization (Boyd & Hunsberger 1998). Children also expected privacy to be included in the quality of paediatric nursing, as was also found by Curtis et al. (2004) and Lindeke et al. (2006).

6.2.2 Children's evaluations concerning the quality of paediatric nursing care

Evaluations of the quality of paediatric nursing care from children's perspective have earlier been relatively little studied. Children rated the quality of their care very highly, as has been the case in previous studies as well, but upon closer scrutiny the results also revealed some problems. (Paper III, IV.) This result is consistent with earlier research findings (Freed et al. 1998, Carney et al. 2003, Curtis et al. 2004, Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007).

Among the main quality categories nursing environment obtained the highest ratings, followed by nurse characteristics and nursing activities. Children rated staff characteristics very highly, especially humanity (Paper I, II) and trustworthiness (Paper I), which is line with earlier studies (Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007). However, in this study only half of the children knew their primary nurse by name. To enable care based on individual needs, care should be provided by a small team of professionals so that each child and parent is familiar with those responsible for their care.

In the main category of nursing activities, children rated caring and communication the highest, while the lowest ratings were given to entertainment activities, physical care and treatment, supporting initiative and education. As a whole, the evaluations were good, with the exception of entertainment activities. According to the children, only three per cent of the nurses always had played with them (Paper III). Children who had been in hospital before were more pleased than those being there for first time with the entertainment provided by nurses; this was also found by Schmidt et al. (2007). This can be explained by their prior knowledge about nurses' work and activities. Although the children did not rate the nurses' entertainment activities highly, their best experiences were mostly related to these activities and the availability of physical objects (Paper IV), consistently with earlier studies (Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007). Children saw themselves as active even they were in hospital. One of the best things in hospital was the opportunity to play, either alone or with parents, friends or nurses (Paper IV). This is an important finding and nurses need to recognize the meaning of playing with children because the lack of activities and being bedridden were among the worst experiences (Paper IV), and it is one of the major stressors of hospitalization (Boyd & Hunsberger 1998). By playing with children, nurses can establish a significant, warm relationship, which helps to create a sense of security and lays the foundation for a trusting relationship between children and nurses. Nurses can and they should integrate elements of play and games into their daily routines; the ability to play with a hospitalized child gives added value to the skills of a nurse caring for children and their families (Haiat et al. 2003).

Earlier studies (e.g. Freed et al. 1998, Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007) have identified patient education and information as a critical quality indicator, which is consistent with results of this study. It was quite alarming to see that only about half of the children had received enough information about leisure activities, home care instructions, going back to school and the duration of hospitalization. There is also earlier evidence indicating that the child's voice is hardly heard at all during the stage of diagnosis and providing advice on home care (Tates et al. 2002, Curtis et al. 2004, Coyne 2006a). Staff's lack of time for discussion can also lead to children not being asked about their views and wishes (de Winter et al. 1999). One possible reason is that in many cases home care instructions are given to parents only. Another reason in this study is that children may have received and answered the questionnaire too early, even though the nurses were instructed to hand out the questionnaires before discharge. Migone et al. (2008) discussed that all health care professionals working with children should be paediatrically trained, including a focus of communication in developmentally appropriate ways and on children's rights. Interpersonal styles of professionals influence the quality of communication as well (Freed et al. 1998, Mah et al. 2006, Shaw 2006a).

The children gave low ratings to nurses' efforts to support their initiative, especially "encouraging me to participate in my own care". One possible reason may lie in the protective attitude of adults as guardians and defenders toward children as well as in the view that children do not have the necessary competence to take part in their care (Lowden 2002). However, in recent years it is increasingly accepted that children themselves should more and more involved in their own care (Coyne 1998, Curtis 2004, Hallström & Elander 2004, Coyne 2006a). Children have needs for participation during hospitalization (Runeson et al. 2002) and they want to be involved in care and decision-making in hospital (Coyne 2006a). Even though they are not always mature enough to make independent choices, they can almost always participate in one way or another in the process of decision-making (Runeson et al. 2002, Coyne 2006a). Also parents have been wanted the health professionals to consult with their children before decisions were taken and enacted upon (Angst & Deatrick 1996, Coyne 2006a). It is therefore important to give children information that is specifically designed for them, with an understanding of their unique development and learning needs (Enskär et al. 1997, Sartain et al. 2001, Magaret et al. 2002, Curtis et al. 2004, Witchell & Lester 2005, Coyne 2006b, Schmidt et al. 2007). Seeking information is a common strategy among school-age children for coping with the stressful aspects of hospitalization (Caty et al. 1984, Alderson 1993, Coyne 2006a) and nurses can help to promote coping by explaining procedures, specifying their actions and telling children what to expect (Boyd & Hunsberger 1998, Wollin et al. 2004). Active participation of children has health-promoting value for them (de Winter et al. 1999).

It was not a great surprise that children's worst experiences during hospitalization were related to physical care and treatment activities and symptoms of illness (Paper IV), as shown in earlier studies (e.g. Carney et al. 2003, Curtis et al. 2004, Chesney et al. 2005, Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007). However, it is important to notice that children were pleased in their pain management in this study, as opposed to other studies made from parents' perspective (Homer et al. 1999, Contro et al. 2002). However, pain was one of the symptoms mentioned as the worst thing, and children were most afraid of injections and pain. It is quite clear that every stay in hospital is bound to involve some things that are not particularly nice.

In this study, children had a very positive assessment of the nursing environment, as also indicated in previous studies (e.g. Sartain et al. 2001, Carney et al. 2003, Coyne 2006b, Chesney et al. 2005, Lindeke et al. 2006). They were satisfied with the company provided by parents or nurses as part of the social environment (Sartain et al. 2001, Carney et al. 2003, Lindeke et al. 2006). However, separation from home and school, parents, family and friends was mentioned as being one of the worst experiences. This is in line with earlier studies (Chesney et al. 2005, Coyne 2006b). The importance of friends and other patients for the quality of paediatric nursing care (Inman 1991, Sartain et al. 2001, Carney et al. 2003) needs to be studied more closely based on children's expectations about friends during hospitalization (see 6.2.1). It is clear that the opportunity for friends to visit as well as contact with other patients is also affected by short periods of hospitalization and by the reasons for hospitalization.

In this study, privacy, the possibility to be in peace, was also mentioned as the best, and the lack of it as the worst experience from children's perspective, consistently with earlier studies (e.g. Sartain et al. 2001, Curtis et al. 2004, Migone et al. 2008). Privacy has been an important part of the quality of nursing care especially among older children (Battrick & Glasper 2004, Lindeke et al. 2006). It is possible that privacy becomes more important with development during adolescence, and it should be taken into account in caring for older children. Privacy could also be related to cultural aspects, i.e. children wanted privacy due to being ill children and for management of pain (e.g. Cleland et al. 2005, Kankkunen et al. 2008).

Every stay in hospital is bound to involve some things that are not particularly pleasant for children, but it is important to look at ways in which any discomfort could be reduced. At least to some extent, the best and worst experiences are related to each other, and in order to achieve a lasting improvement in quality, both have to be taken into account simultaneously. The results collected by the "Child Care Quality at Hospital" were partly supported and given more depth by sentence completions. Practical measures aimed to improve the quality of nursing care for children should indeed focus on eliminating and reducing these sources of worst experiences while strengthening the sources of best experiences.

6.2.3 Development of the Quality Instrument "Child Care Quality at Hospital" (CCQH)

The results of the review of quality instruments (chapter 2.3) showed that there is a shortage of instruments designed specifically for children (Rifkin et al. 1988, Simonian et al. 1993, Freed et al. 1998, Mah et al. 2006), and especially for the use of nursing care. The content of previous instruments focuses mainly on the interaction between the child and physicians (Rifkin et al. 1988, Simonian et al. 1993, Freed et al. 1998), on provider's attributes (Rifkin et al. 1988), family-centred care (Mah et al. 2006) or on using the general Client Satisfaction Questionnaire (CSQ, Freed et al. 1998, Mah et al. 2006). Instruments have been used for children aged between 6 and 21 years. In some studies (Magaret et al. 2002, Battrick & Glasper 2004, Chesney et al. 2005, Witchell & Lester 2005, Mah et al. 2006, Shaw et al. 2006a, 2006b) nearly the same instrument has been used for children age between 4 and 19 years and their parents (see Table 2). In the paediatric field, most of the instruments (Vandvik et al. 1990, Dawson & Mogridge 1991, Simonian et al. 1993, Budreau & Chase 1994, Brown et al. 1995, Davis 1995, Thornton 1996, Marino & Ganser 1997, Glasper et al. 1999, Homer et al. 1999, Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, 2004, Brágadottir & Reed 2002, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Aitken & Wilshire 2005, Ammentorp et al. 2005, Haines & Childs 2005, Miceli & Clark 2005, Ammentorp et al. 2006, Mah et al. 2006, Pritchard & Howard 2006) have been developed for parents and they have mainly evaluated the quality of their children's care, although the child should also be seen as a customer in paediatric care (Carter 1998, Hart & Chesson 1998, Curtis et al. 2004). At the same time, there is a growing recognition of the importance of children's rights, the need to listen to them and consult them both at national and international level (e.g. United Nations 1989, Council of Europe 1996, 1997, Department of Health 2003, STM 2008a). All these reasons clearly highlighted the need to create a valid, reliable and easy-to-use instrument for evaluations of the quality of paediatric nursing for children.

The basis of the designed instrument, the "Child Care Quality at Hospital" CCQH, lies in children's expectations about the quality of paediatric nursing care (Paper I, II). Besides, previous literature and Leino-Kilpi's "Good Nursing Care" quality categories: nurse characteristics, nursing activities and nursing environment (Leino-Kilpi & Vuorenheimo

1992, 1994, Leino-Kilpi et al. 1994, 1999) were used during the development process. The instrument was developed in three steps (Phase II). The quality of care is viewed as an action process with related contributing factors; nursing involves human action carried out by an agent in an operational setting (Leino-Kilpi & Vuorenheimo 1994). The theoretical construct of the instrument seems to be clear, but further testing is needed. The validity and reliability of the instrument was already discussed in more details in chapter 6.1.2.

The development process yielded a general quality instrument CCQH IV for school-aged children used in inpatient hospital settings (V). During the development process, the instrument was shortened from the original 66 items to 49 items in the final version CCQH IV. However, there may still be too many items for the youngest school-age children, because they needed more help with reading, understanding the questions and writing. More testing will thus be needed to evaluate the suitability of the instrument especially for children aged 7 years. Rebok et al. (2001) found also in their study that 8-year-old children are able to report on all aspects of their health experience and their term understanding is better compared to that of 6- and 7-year-olds. Furthermore, parents may have a greater influence on the responses of the youngest children (e.g. Kortesluoma et al. 2003, de Leeuw et al. 2004). Simonian et al. (1993) minimize the potential effect of social desirability response bias by using by an abbreviated version (5-item) of the Children's Social Desirability Questionnaire (CSD). If children answered four or more screening question in a socially desirable direction, they were omitted. However, a more effective way could be using a brief test to measure the ability of children to read, understand what they read and to write before completing the instrument. Research on attitude questions indicates that response reliability declines as the length of the questions increases. However, in the case of children longer questions and/or using longer introductions to the question has a positive effect on response quality. (Holaday & Turner-Henson 1989, de Leeuw et al. 2004.) The length of the instrument has also been shown to be problematic in quality and satisfaction surveys among adults (Thomas & Bond 1996).

The instrument "Child Care Quality at Hospital", CCQH, can be used in general paediatric hospital settings for school-age children. The main quality categories cover general issues about nursing care in paediatric settings. The instrument has been used in different paediatric and paediatric surgical wards in Finland (Paper III), and only one or two items were not relevant for wards (e.g. "other patients provide company"). Some alterations need to be made in the case of using it in out-patient settings. However, most of the items are appropriate for out-patient care as well, such as those concerning information. In terms of clinical practice, one possibility is also to use only one of the main quality categories; for example, to evaluate improvement in nursing activities from children's perspective. However, to evaluate only nurses' characteristics is not relevant for the quality assessments. The use of this instrument could give valuable baseline data about children's evaluations as to happen during their hospital care and assist in identifying key areas for quality improvement. Particularly, the instrument gives information about children's expectations that are not met during the care. It could be used in the context of different interventions and for analysing the outcomes of interventions. For example, educational interventions could be implemented and this instrument could be one of the outcome measurements, adding to other relevant instruments. In clinical practice it could be used for children together with parents to find out congruence between parents evaluations and children's evaluations. Based on previous studies, there are differences between children's and their parents' quality assessments (Simonian et al.1993, Magaret et al. 2002, Chesney et al. 2005, Shaw et al. 2006a), and this gives reason to evaluate the quality of paediatric nursing care also from children's perspective. The instrument gives nurses an opportunity to listen to children's voices. In the future, it would challenging to connect some other instruments to the "Child Care Quality at Hospital" instrument to get a better and broader analysis about the quality of paediatric nursing care and how it is related to e.g. health-related quality.

The CCQH instrument is a potential tool for obtaining knowledge about children's evaluations of the quality of paediatric nursing care, and thereby contributing to improved quality in practice with a more genuinely child-centred approach. However, construction of the instrument is a never-ending process and it needs further testing and evaluation in the future.

6.3 Conclusions and suggestions

This study set out to examine the quality of paediatric nursing care from children's perspective and to develop and test an instrument for school-age children. This study also provides systematic knowledge about quality instruments used in paediatric care. In order to improve the quality of paediatric nursing care on the basis of the research results, the following conclusions may be drawn in view of the limitations of the study.

Children's expectations of the quality of paediatric nursing care

1. Children's expectations concerning nurses included humanity, trustworthiness, having a sense of humour, using colourful clothes; young boys expected nurses to be male. These are factors that could be expectations related to physicians as well, because especially young children may find it difficult to describe and notice the differences between a nurse and a doctor, because these professionals usually collaborate and work in multiprofessional teams. In terms of improving paediatric care, it is not even necessary to separate the personal characteristics of these groups of professionals.

2. Children expected especially entertainment and education activities to be part of the quality of nursing care. The world of play is particulary important to all children, also in hospital. The ability to play with a hospitalized child is a crucial skill for nurses specializing in the care of children. Nurses should integrate elements of play into their daily routines, for example by utilising play and games when giving instructions or information about treatment and care to the children. In nursing education, the basis for understanding playing as an important aspect in peadiatric

care should be taught. Nurses should also develop further their playing skills, and these skills should be included in the programmes of continuing education and orientation periods of new nurses in paediatric wards.

3. Children expected to receive information and explanations aimed directly at them; they wanted to know what is going to happen during hospitalization. Children should be seen as active partners in their care and they have a right to be informed in the manner appropriate to their age and understanding. Patient education and information is one of the fundamental nursing activities. In paediatric care, there is a need to develop further and test educational activities and their outcomes for children of different ages.

4. Children expected nursing activities from their parents: safety, caring and entertainment. Parents have an important role in the quality of paediatric nursing care: they relieve fears and longing during hospitalization as well as provide the children company and help with daily activities. Society should promote parents' possibilities to be at hospital during children's hospitalization. The parents' contribution to the quality of paediatric nursing, as seen from the children's viewpoint, should be further investigated, and parents should be encouraged to relieve the child's fears, for example. It is clear that parents are unsure about their skills and need support on the part of nurses.

5. Children had both social and physical expectations with regard to the nursing environment. Other children, whether friends or other child patients on the ward, play a role in quality nursing. More attention should be given to the meaning of other patients for children and how nurses could use the peer group for support in acute care and during short hospitalization as well. On the other hand, nurses need to provide privacy for children, who expected privacy more than friends. Children's expectations of physical environment in terms of the quality of paediatric nursing care focus on entertainment to pass the time and pleasant patient rooms. Nowadays, the paediatric wards are quite well equipped with entertainment activities, but there can be a lack of parental accommodation instead. Attaining privacy requires that children in hospital do not need to experience unnecesssary painful operations.

6. Children's drawings were used for data collection. Together with the interviews, it was a relevant additional method to find out children's expectations and quality elements; it was also suitable for children aged from 4 to 11 years. Children should, however, draw more than one drawing. The use of drawings should be tested further in clinical practice and nursing research.

Children's evaluations concerning the quality of paediatric nursing care

1. Children mainly rated the quality of paediatric nursing care as being excellent with the "Child Care Quality at Hospital" instrument; however, a more detailed analysis also indicates some lower ratings. Besides, open-ended sentence completions at

the end of instrument produced some additional information that gave deeper understanding about some quality indicators. These more challenging indicators are symptoms of illness, especially pain, separation from home, family and friends, being bed-ridden, lack of activities, no privacy and especially different procedures, food restrictions and waiting. All these are aspects which should be given special attention in trying to find solutions, if the aim is to improve care so as to fulfil children's expectations better.

2. Children gave nurses' entertainment activities a low rating: they were not satisfied with the amount of information received and nurses' supporting initiative activities. Children's participation and involvement in care should be supported with nursing activities. One way to do this is through the provision of information and by encouraging children to ask about their care. Education and information aimed at children should be more clearly oriented to their needs and to making sure that children understand what is happening. Greater attention should also be given to producing information aimed at children, especially to developing new appropriate methods and the use of entertainment activities such as plays, games, multimedia presentations and websites for informing children. Besides children admitted for emergency procedures and youngest school-age children, more attention should be focused on information related to discharge and home care especially among school-age children.

3. Hospitalization is a stressful event for children. In order to reduce initial anxiety and negative experiences, care should be taken to reduce the worst experiences and to prepare children and their families for hospitalization. Intrusive events and procedures and treatments are an obvious source of stress for hospitalized children, but nurses should use innovative child-centred strategies and activities, especially those involving entertainment, to reduce or eliminate the worst experiences. Good communication between nurses and children and their families is linked to an increased understanding of treatment and illness.

4. The quality of paediatric nursing care was evaluated by children who were capable of expressing their views. However, there is a trend in paediatric nursing care to use mainly parents' evaluations. Children should be seen as more active partners in paediatric care. Health professionals should be committed to engaging children in the quality process and to incorporating their views into service delivery, which should lead to more focused and relevant services for children.

The Quality Instrument "Child Care Quality at Hospital" (CCQH)

1. The "Child Care Quality at Hospital" was developed in three steps for school-age children from 7 to 11 years of age, based mainly on children's expectations concerning the quality of paediatric nursing, previous literature and Leino-Kilpi's "Good Nursing Scale". The validity and reliability of the instrument was improved during the developing process, and are now mainly satisfactory for a

new instrument. However, more testing should be done in the future. Particularly, there is a need to use it in other fields of children's care.

2. There is a shortage of instruments designed for quality evaluations aimed at children themselves. This instrument fills this gap and is especially designed to measure paediatric nursing care. However, when children evaluate care it is not obvious to them to distinguish between nursing and medical care, and quality managers and practitioners need to consider how relevant it is to separate activities of different professional groups. It might be useful to have a common instrument for evaluating quality first and then produce some specific instruments for specific purposes. It would be important for organizations to obtain general information about quality and if needed, specific information could be collected as well.

3. The quality of paediatric nursing care has to be measured systematically. The instrument developed in this study can be used on paediatric wards as a regular instrument or part of it. This will provide a constant flow of information on children's evaluations and an invaluable tool for the purposes of quality improvement. The results could be used e.g. in nurse education as well as hospital environment planning.

4. The basic elements of the quality of nursing care are taught in basic professional nursing and health care education. This instrument, "Child Care Quality at Hospital", could also be used for educational purposes. For example, nursing students could evaluate the same variables from their perspective and then compare their evaluations with those of children; it would help them to understand the important quality factors of clinical practice in their wards.

6.4 Suggestions for future research

Research on the quality of paediatric nursing care is highly advisable in the future. There will also be a need to increase research in this field, and this study indicates several suggestions for further research. These suggestions can be divided into the following areas: a) suggestions in the clinical field, b) suggestions in health care and nursing administration and quality management of organizations, c) suggestions for further development and testing of the instrument, d) suggestions in the field of nursing education and e) suggestions in the field of nursing science.

Suggestions in the clinical field

1. There is need to develop child-centred age-appropriate patient education methods for children and especially to develop children's participation in the discharge process to capture children's information needs. This would require testing new interventions and evaluation of their effectiveness by randomized clinical trials. There is also a need to make systematic reviews in the field of paediatric patient education and to analyse the patient education instruments available. Furthermore,

information leaflets and programmes could be analysed, looking for effective methods for children of different ages. In the paediatric field, various health technology solutions for patient education would be worth testing.

2. More research is needed to explore parents' and other child patients' influence on the quality of paediatric nursing care. In this study, an instrument for evaluation of quality of care has been developed, and this instrument could be used as one variable in testing different quality programmes. In addition, there is a need to conduct deeper interviews about the possibilities of parents and children to participate in joint decision-making.

3. There is a need for intervention research in other clinical fields as well. First, intervention studies should be conducted to find out methods to prevent or reduce the pain or fear related to physical care and treatment, this being an important element in the quality of nursing care. Second, intervention studies are also needed in order to find new ways to empower children to take part in their care. Third, evidence is needed to discover how to prepare children better for hospitalization and the discomfort that every stay in hospital is bound to involve.

4. Follow-up studies in the evaluation of the quality of care would be welcome. In these, the "Child Care Quality at Hospital" instrument could be used to find out the meaning of time and place for children's evaluations, as well as find out the best and worst memory a few weeks after discharge.

5. There is a need for more research from children's point of view in paediatric nursing to increase the possibility of children to participate in their own care. Children's participation in their own care should be studied by looking at their communication and interactions with nurses and doctors to find out the most effective ways to foster children's commitment to their own care, especially among children with chronic diseases.

Suggestions in health care and nursing administration and quality management

6. Parents' and nurses' evaluations of the quality of paediatric nursing care should be explored at the same time with children's assessments to find out whether they evaluate the quality of care in the same way or whether there are differences. Within health care organizations, it would be important to have as much information as possible about the quality indicators. Thus, those responsible for quality management should also include different evaluations from family members, children and parents in the overall assessment. This would allow a more comprehensive view over quality.

7. Follow-up studies should be conducted annually at hospital and ward level to find out the level of the quality or changes in it and the sensitivity of the instrument to measure those.

Suggestions in the field of instrument development and testing

8. The "Child Care Quality at Hospital" instrument seems to be valid for the evaluation of quality. However, there are still some components that need to be developed further. Especially items related to outcomes of care should be added to the instrument and be tested based on children's best and worst experiences. The instrument could also be tested in different settings to gain more evidence of its psychometric properties.

9. Future research is needed to make sure the instrument is suitable for completion by children whose cognitive, communicative and social skills depend on their age. Deeper insights into children's preferences can be gained by using qualitative methods to verify the relevance and the concept to children.

10. The instrument should be tested and modified for use in outpatient as well as psychiatric settings, too. Besides, there is also a need for a quality instrument for children under school age.

11. Generally, there is a need for research to develop and evaluate suitable methods to conduct research with children.

Suggestions in the field of nursing education

12. Nurses' and nurse students' knowledge and skills should be updated so that they properly understand the idea of quality indicators from children's perspective.

13. There is a need for specialization courses in children's play at hospital for nurses as well as patient education aimed at children. In current nursing education in Finland, there is no specialization education in the paediatric field, as was earlier the case. Emphasis should thus be given to continuing education. In addition, paediatric nursing is a field requiring various skills and knowledge. There are no university-educated clinical nurse specialists in this field in Finland, and this is something that should be considered.

Suggestions in the field of nursing science

14. In nursing science, empirical research in paediatric nursing from children's perspective is still rare. This study indicates that an innovative research approach is needed, and the suitability and validity of different methods for children of different ages should also be tested in the field of nursing science. Furthermore, research should be focused on children under school age.

15. It would be a challenge to construct a theory in the field of paediatric nursing about children's hospitalization, and especially to find out whether it is affected by or associated with quality indicators.

Most of these suggestions are relevant both internationally and nationally in Finland.

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Appendix 1. Studies on the quality of paediatric care from children's perspective.

Author, year, country	Purpose	Sample	Method	Main findings
Freed et al. 1998, USA	To better understand the determinants of adolescents' satisfaction with their health care providers and to examine the relationships between satisfaction, intention to return to follow-up, and appointment-keeping behaviour	124 adolescents (12-21 yrs)	Questionnaires (satisfaction was measured with the Client Satisfaction Questionnaire)	Pre-visit attitudes about providers' style of behaviour predicted satisfaction ($p < 0.01$). After controlling for pre-visit attitudes, perceptions about providers' style of behaviour proved to be a strong predictor of visit satisfaction ($p < 0.01$). Visit satisfaction was associated with intention to keep scheduled follow-up appointments ($p < 0.01$).
Carney et al. 2003, Scotland	To investigate a broader range of experiences in a general paediatric population, and to determine the most effective way of obtaining the information	213 children (4-17 yrs)	Questionnaires, four different types	The themes identified were generally positive and mainly related to the children's physical surroundings. A verbal structured questionnaire was found to be the most efficient in obtaining the children's views, whereas a visual structured questionnaire was the only method which recognized the children's sequence of feelings before, during and after hospitalization.
Curtis et al. 2004, UK	To identify what children and young people in a health district in a large urban area experience as positive – and not so positive – about their local health services, in the light of a growing expectation that users play a more central role in the design and delivery of services	92 children from community and 57 from clinical settings (4-19 yrs)	Interviews, play techniques and website	Alongside planning and environment issues, young people particularly emphasized the impact of communication and relationships with staff on their experience of health services.
Lindeke et al. 2006, USA	To query children about the perceptions of their inpatient healthcare experiences in order to improve care to make it more developmentally appropriate and responsive to children's needs and desires	120 hospitalized children (4-20 yrs)	Interview	Pain and discomfort were cited most frequently as the worst aspects of hospitalization and the areas most needing improvement. Play activities were valued by children of all ages. Their positive relationships with hospital staff were frequently described.
Coyne 2006, UK	To report on children's experiences of hospitalization	11 children (7-14 yrs)	Interview	The children identified a range of fears and concerns, which included: separation from parents and family, unfamiliar environment; investigations and treatments; and loss of self-determination. The children's loss of self-determination over personal needs exacerbated their fears and concerns.
Schmidt et al. 2007, USA	To contribute knowledge concerning hospitalized children's perceptions of nurses and nurse behaviours based on the words of children	65 hospitalized children (5-18 yrs)	Interview	Children appreciated nurses who smiled and used kind words, took measures to reduce pain, provided age-appropriate diversion and light-hearted conversation, promoted positive well-being and a sense of security, provided food and medicine, interacted with them as an individual and provided comfort and support.

Appendix 2. Studies on the quality of paediatric care from children's and parents' perspective.

Author, year, country	Purpose	Sample	Method	Main findings
Kvist et al. 1991, Finland	To compare impressions formed by sick children with leukaemia or lymphoma with the impressions of parents about disease-related changed in significant relationships and environmental attitudes, and similarities and discrepancies in perceptions of treatment-related problems and on patients' and parents' satisfaction with regard to the quality of the care of the malignancy during the induction and maintenance therapies	53 children (6 -19 yrs) and their parents during the 11-year period of 1976-1986 treated at the University hospital	Self-developed questionnaires for the children and the parents during induction and maintenance-therapy	Parents were more satisfied with the induction therapy than the children ($p< 0.05$) and the parents' satisfaction with the quality of care provided did not differ ($p>0.05$) between induction and maintenance therapy. The children had fewer complaints about the quality of care during the maintenance than about that of the induction-therapy ($p <0.05$). Children's complaints were most often about the quality of care during induction, namely pain, fear and insufficient information. Parents' complaints were about the lack of continuity in staff-patient relationship during maintenance therapy.
Simonian et al. 1993, USA	To develop a measure of paediatric patient satisfaction that could be used with diverse patient groups	55 mothers, 55 children (6-14 yrs)	The Metro Assessment of Child Satisfaction (MACS) questionnaire for children, the Pediatric Satisfaction Questionnaire (PSQ) for mothers	Findings indicated that the MACS is internally consistent and easily administered and understood by children as young as 6 years of age. Factor analysis yielded four distinct factors that appear to be statistically valid and clinically meaningful.
Enskär et al. 1997, Sweden	To identify children's experience of problems related to their cancer and the disease effect on the child's life situation	5 children (6-12 yrs), 5 parents	Interview	Six categories regarding influencing factors on the children's life situation were found: 1) medical treatment and side effects, 2) isolation, 3) togetherness and support, 4) being in the centre, 5) feelings and reactions, and 6) quality of care.
Sartain et al. 2001, UK	To compare families' experiences of hospital and home care, to evaluate the clinical and cost effectiveness of a paediatric hospital at home service (HAH) for acute illness in children	40 families, 11 children	Interview, drawings	Hospital at home service (HAH) is an acceptable alternative to hospital care where there are essentially nursing needs. Thirty-six (90%) parents and seven children stated a clear preference for HAH. The social and financial costs of hospital care compared with HAH were other main drivers, rather than a comparison of the quality of nursing care of their child.
Magaret et al. 2002, USA	To assess and compare overall satisfaction in paediatric emergency department (ED) patients and their accompanying parents. To identify aspects of health care delivery that influence satisfaction in these groups	101 pairs, children (5-17 yrs) and their parents or guardians	Questionnaires	Parent satisfaction was associated with the quality of provider-patient interactions ($p= 0.0001$), the adequacy of information provided ($p=0.0001$), and shorter waiting room times ($p=0.01$). Child satisfaction was associated with the quality of provider-patient interactions ($p=0.04$), adequacy of information provided ($p=0.003$) and resolution of pain ($p=0.03$). Parent estimates were similar to children's initial pain scores; however, children reported greater solution of pain than was appreciated by their parents ($p=0.006$).
Battrick & Glasper 2004, UK	To ascertain the views of families on the care they had received during a period as hospital inpatients in an acute area of regional children's unit, to compare the views of adult carers with those of children	50 families with 12 children (4-10 yrs) and 13 young people (11-16 yrs)	Questionnaires	Parental sleeping and other social arrangements were subjects to some critical review; the nursing care experienced by families was highly rated. Although arrangements for discharge were deemed satisfactory, 38% of carers had to wait for medicines to arrive on the ward before they were able to go home. Attempts to include the voice of the younger child in this study proved unsatisfactory as parents elected to act as proxies in completing the child-specific questionnaires.

Chesney et al. 2005, USA	To compare children's ratings of patient satisfaction with outpatient care to ratings given by parents	116 children and adolescents (4-19 yrs) and 115 parents	"Satisfaction with Child Healthcare Survey" Questionnaire adapted version from "Kids Count Survey"	There was a moderate significant correlation between child-teen and parent scores. Parents rated care significantly higher than did the children. Children's responses to open-ended questions varied somewhat from their parents' opinions on various aspects of clinic visits.
Witchell & Lester 2005, UK	To ask children and their families about their visit to the hospital outpatient department, to find out if children and their families were aware of PALS (The Patient Advice and Liaison Service) and how to contact the service, and provide an opportunity for children and their families to make other comments	50 parents, 50 children (3-6 yrs), 50 children (7-11 yrs)	Questionnaire	Parents reported receiving good information prior to and during the consultation but would like more written information to take home. The environment was rated positively, but older children felt that the waiting area was lacking in appropriate activities to suit their needs. Very few respondents had heard of PALS and around half did not know who to approach with concerns.
Mah et al. 2006, Canada	To describe adolescents' responses to a client satisfaction and family-centred care survey, to examine the relationships between satisfaction with health care and health-related quality of life (HRQL) among these adolescents; and to determine if adolescents and their parents differ in their satisfaction with services	104 family (parents and adolescents 12-18 yrs)	The Client Satisfaction Questionnaire (CSQ), the Family Centered Care Survey (FCCS), the Measure of Processes of Care (MPOC) survey, The Give Youth Voice (GYV) survey, the Pediatric Quality of Life Inventory (PedsQL)	The majority (83%) of adolescents were satisfied with services provided. Adolescents who were very satisfied on the CSQ and the FCCS had higher PedsQL psychosocial scores. Multivariate analysis revealed that adolescents' psychosocial HRQL was the most significant predictor of their satisfaction with care. There was a difference between parents' and adolescents' responses to the FCCS, with adolescents being less satisfied overall.
Shaw et al. 2006a, UK	To examine the quality of transitional health care from the perspectives of young people with juvenile idiopathic arthritis (JIA) and their parents	308 adolescents (10-18 yrs) with JIA, 303 parents/guardians	Questionnaires	Young people and their parents rated provider characteristics more important than aspects of the physical environment or process issues. Staff honesty and knowledge were rated as the most essential aspects of best practice. Prior to implementing the programme of transitional care, parents rated service delivery for all items significantly worse than best practice. Parents' satisfaction improved on 70.4% of the items, significant improvements were only observed on three (13.6%) items rated by adolescents.

Appendix 3. Studies on the quality of paediatric care from parents' perspective.

Author, year, country	Purpose	Sample	Method	Main findings
Vandvik et al. 1990, Iceland	To assess parent satisfaction with hospital care and needs for improvement	106 parents of children with juvenile rheumatic diseases	Questionnaire, interview	95 - 98 % of parents were satisfied with the way they had been received, the ward setup and the atmosphere, the examination of the child by the physicians and the examination and treatment by the physiotherapists, whereas 86 % were satisfied with information regarding illness and treatment. Dissatisfaction positively correlated to mental distress of the mothers at the first stay and their assessment of disease severity at follow-up.
Dawson & Mogridge 1991, New Zealand	To assess the parents' perceptions of the quality of care given	206 parents of children admitted to paediatric department, 4-6 days after their child's discharge from hospital	Telephone interviews based on self –developed questionnaire with 11 categories about parents satisfaction: admission process, history taking, information illness, planned treatment, information about facilities, nursing, overall management, procedures, future illness, medicines and overall satisfaction	Overall satisfaction was in the order of 86%. Areas of discontent were in the admission process, information about available hospital facilities and information on the future management of the child's illness.
Price 1993, Canada	To describe the meaning of quality nursing care to parents of hospitalized children and to identify concepts inherent in the process of receiving quality nursing care	4 parents of hospitalized children	Interview	Four stages in the process were identified: maneuvering, process of knowing, positive relationships and quality care. Quality was clearly described as care that involved positive reciprocal interactions between nurses and the child and parent.
Brown et al. 1995, Australia	To evaluate parents' satisfaction with the services provided in an emergency department located at a paediatric hospital	124 parents	The Client Satisfaction Questionnaire (CSQ) and self-developed questionnaire	The majority of parents were satisfied with the services provided. However, less satisfied parents reported having to wait significantly longer before receiving medical attention than satisfied parents. Less satisfied parents were concerned about the speed with which their child's needs were met, the availability of staff, and the quality of staff communication with parents.
Davis 1995, UK	To ascertain parents' perceptions about the care their children receive whilst attending the Accident and Emergency department, to highlight negative aspects of care, and increase understanding and knowledge regarding the needs of parents and children in the Accident and Emergency environment	107 parents whose children under 10 years old has treated in the A& E department of a district general hospital, 10 parents	Questionnaire, Interview	Main themes relating to parents' satisfaction with nurses were staff attributes communication and professional. Negative remarks related primarily perceived lack of communication and lack of indication of the waiting time.
Thornton 1996 USA	To determine the degree of congruence between parents' satisfaction with nursing care on a paediatric neurosciences unit and nurses perceptions of parent satisfaction	20 parents of hospitalized children and 20 nurses from the neurosciences unit	The Adapted Patient Satisfaction Instrument (APSI) (Risser) included three subscales: Professional (7 items), educational (7 items) and trust (11 items)	The high level of satisfaction with nursing care reported by the parents indicates that the nurses' helping behaviours were meeting the parents' expectations at the time of the study. Nurses' perceptions of parent satisfaction with nursing care were not congruent with parents' reported satisfaction. The differences in means are remarkably consistent, being in the range of .30 to .33.
Callery & Luker 1996, UK	To describe the experiences of parents of children discharged from a surgical ward of a children's hospital	24 parents	Interview	The qualitative methods have value in the assessment of user satisfaction with care. A particular strength of qualitative methods of inquiry is that limitations of user's choice in care can be assessed.

Author, year, country	Purpose	Sample	Method	Main findings
Marino & Ganser 1997, USA	To determine the relationships between structures (LOS=length of stay and skill mix), processes (as measured by parent report of care), and outcomes (parent evaluation of care and parent evaluation of LOS), over a 5-years period encompassing planned organizational change	3622 parents	The Clinical Consumer Survey (CCS) partly, 15 items related to aspects of nursing care, 4 items related to evaluation of nursing practice and one item on which families rate the LOS	Parents saw no difference in nursing care provided, and rated care similarly at every round of the survey. Patient report of care should not be a primary measure of the effect of organizational change on nursing care.
Glasper et al. 1999, UK	To explore parental satisfaction during their visit of paediatric outpatient nursing development unit	127 parents	Questionnaire	Overall the results demonstrate a high degree of satisfaction with the outpatient visit family experience: Families view a more informal uniform positively.
Homer et al.1999, USA	To develop a measure of parental perceptions of paediatric inpatient quality of care, to identify processes of care that influence these perceptions, and to describe these perceptions of care	3622 parents of hospitalized children in tertiary care paediatric hospital from 1991 through 1995	The Picker/Commonwealth Patient Centered Care survey, modified version including 122 items with 6 broad dimensions of care: information to parents, information to the patient, partnership in care, pain management, surgical issues and hospital discharge planning	Parents most often noted problems related to hospital discharge planning (18%) and pain management (18 %) and less often reported problems concerning communication about surgery (10%) or transmission of information to children (6%). Problems in communication between clinicians and parents correlated most strongly with overall quality ratings by parents (r. 0.59). Patients with chronic conditions, in poorer health status, of low income, minority, non-English speaking, and those not undergoing a surgical experience all rated the care lower and indicated more problems across most dimensions of care.
Stubblefield & Murray 1999, USA	To determine parents' perception and expectations of health care providers whose children have undergone lung transplantation	15 parents	Interview	Two theme cluster, concerned care and collaborative care wee formulated by parents. Parents' perceptions of concerned care included: being treated as an individual, seeing familiar faces, feeling that their children really mattered. Parents' perceptions of collaborative care included: being part of the team.
Marino & Marino 2000, USA	To determine the aspects of nursing practice that are predictive of parent satisfaction with their child's hospital care	3299 families cared for 12 nursing units and surveyed in 6 waves of the survey from 1995 – 1998	Self developed questionnaire, 60 items, 15 of these about nursing care. Study focus on these and the rating of overall care	Nursing unit was significantly related to overall satisfaction with care (<.0001). Overall, 60 % of the 3299 families rated care as "excellent". Of the fifteen questions related to nursing care, 7 were highly associated (p<.001) with overall satisfaction with care. The questions that are most predictive of overall satisfaction all ask if nursing practice was tailored to the needs of the parent or child.
Filani 2001, Saudi Arabia	To determine the overall client's satisfaction with care provided during children's/ wards' hospital-stay and to identify areas of dissatisfaction that need to be improved upon	100 mother of hospitalized children	Client Satisfaction Questionnaire (CSQ)	Over 80 % of mothers were satisfied with the care provided during hospital stay of their children/wards. 88 % were satisfied with their "Experience with nurses" while only 68 % were satisfied with information provided during orientation on admission.
Shields & King, 2001 Australia, Britain, Indonesia, Thailand	To determine attitudes of parents of hospitalized children about the care of their children	76 parents of hospitalized children in a total of 23 hospital in Australia, Britain, Indonesia and Thailand	Single and focus group interviews and 2 vignettes	Parents in all countries were primarily concerned with treating the child's illness and the child's recovery. Parents were concerned with their work, but this was a much larger consideration in Indonesia and Thailand, where no security systems exist, than in Australia and Britain. Communication with staff was the most commonly mentioned theme for parents, indicating that irrespective of the culture in which the care was given, good communication between parents and staff was of paramount importance.
Contro et al. 2002, USA	To obtain personal accounts of families' experiences to learn ways to improve care for paediatric patients and their families	68 participants, representing 44 families, whose children had died and had received palliative care	Interview	Several areas of unsatisfactory interactions with staff were identified: confusing, inadequate, or uncaring communications regarding treatment or prognosis; preventable oversights in procedures or policies; failure to include or meet the needs of siblings and Spanish speaking family members; and inconsistent bereavement follow-up.

Author, year, country	Purpose	Sample	Method	Main findings
Cygan et al. 2002, USA	To examine how parents of children with bleeding disorders defined quality health care, their expectations for care at the clinic, and indicators of quality health care important to them	54 parents	The Quality of Health Care Questionnaire (QHCQ) and two open-ended questions	The most important indicators of quality care to parents were being included in decisions about their child's care, being cared for by nurses who are competent and up-to-date, and being cared for by doctors who are competent and up-to-date.
Co et al. 2003, USA	To describe the quality of paediatric inpatient care as perceived by parents of hospitalized children and test whether hospital characteristics (academic status, market competition, freestanding children's hospital) are associated with variations in quality	6030 parents	The Pediatric Inpatient Survey (PIS) measures 7 dimensions of inpatient care quality: partnership, information to child, physical comfort, confidence and trust, and continuity and transition	Parents on average rated their child's care as very good but reported problems with 27% of the surveys' hospital process measures. Information to child (33%) and coordination of care (30%) had the highest problem rates. Parent communication problems correlated most strongly with overall quality of care ratings.
Lawoko & Soares 2004, Sweden	To compare parents of children with congenital heart disease (PCCHD n=1092) with parents of children with other diseases (PCOD, n=112) regarding satisfaction with their children's care (SCC) and to examine the association between parental /patient characteristics and SCC	1092 parents of children with congenital heart disease (PCCHD), 112 parents of children with other diseases (PCOD)	The Satisfaction Children Care (SCC)	PCCHD were more satisfied with their children's medical care and waiting period for treatment of their ill children than PCOD, although the difference was only modest. Furthermore, mothers were less satisfied with staff attitudes than fathers, with the lowest satisfaction among mothers of children with COD. Less satisfaction with care was more associated with decreasing child age, unemployment, financial burden of disease, social isolation and psychological distress than with children's diseases, their severity and parental gender.
Stratton 2004, USA	To explore parents' experiences of the care they received for their hospitalized children	6 parents	Interview	Parents experience childcare in a hospitalized setting in terms of four interconnecting, circular processes: 1) facing boundaries, 2) attempting to understand, 3) coping with uncertainty and 4) seeking reassurance from caregivers. Parents use the parent-caregiver relationship to help cope with their child's condition, and this in turn influences the parents' sense that their child's need are being met.
Ygge & Arnetz 2004, Sweden	To examine whether there were differences in quality ratings between respondents and non-respondents to a questionnaire concerning parents' views of paediatric care	694 parents, 70 parents	The Quality of Care Parent Questionnaire	Analysis of variance revealed that respondents to the follow-up questionnaire who had never received the main questionnaire did not differ significantly from respondents to the main questionnaire in their ratings of key quality domains. There were no statistically significant differences in quality ratings between parents who responded to the both questionnaires and parents who responded to the main questionnaire.
Aitken & Wiltshire 2005, UK	To explore the views of parents and cares on their ability to care child in the days and hours following discharge	40 parents of children discharged from paediatric emergency	Questionnaire	Parents revealed overall satisfaction with many feature of this nurse-led service. Lack of space often compromises privacy, but the majority of respondents were complimentary about the overall standards of cleanliness, the décor and atmosphere.
Ammentorp et al. 2005, Denmark	To identify parents' priorities and satisfaction in relation to paediatric care to assess nurses' and physicians' ability to provide care and treatment that fulfil parents' needs	253 parents in the first section and 170 parents in the second section parents of children admitted consecutively in a paediatric acute care inpatient department	Questionnaires consisted of six domain of quality: access to care and treatment, information and communication related to care and treatment, information related to practical conditions, doctors behaviour, nurses behaviour, access to service	The greatest gap between priorities and satisfaction was in the waiting time related to admission, waiting time related to fulfilment of child's needs, and information given about care and treatment. Parents were most satisfied with the nurses' behaviour; however, physicians' performance was given the highest priority score.

Author, year, country	Purpose	Sample	Method	Main findings
Haines & Childs 2005, UK	To develop and implement a user-friendly, evidence-based survey tool that : 1) addressed the key concerns of parents who access the PIC service, 2) provided an insight into parental perspectives of the service and aided its progression, 3) facilitated evaluation of a service and 4) could be used in ongoing evaluation of the service	110 parents	Questionnaire	There was a high level of parental satisfaction with many aspects of the service, particularly the standard of care, the perceived competency of staff and the level of support and involvement experienced. Respondents provided suggestions for service development regarding information, communication and preparation for the transition from PIC to ward environments.
Heller & Solomon 2005, USA	To explore parents' perceptions regarding continuity and coordination of care of children with life-threatening conditions	36 bereaved parents of children who died after receiving care at hospitals	Interview	Parental concerns about the experience of continuity of care were framed primarily in terms of the quality and continuity of relationships with the healthcare providers throughout a child's illness and death and the continuity and consistency of information that they received about their child's condition and care. In the absence of continuous, caring relationships with staff, parents reported frustration, hypervigilance, and mistrust about the quality of care.
Miceli & Clark 2005, USA	To describe the perspectives of parents whose child experienced a hospitalization	50 446 parents of treated at US hospitals	The Press Ganey Pediatric Inpatient Survey	The most global level, overall satisfaction with the paediatric care experience from the parent's perspective is good to very good, but differs based on facility type. The data reported here suggest that greater specialisation might also translate into higher parent satisfaction, at least with some aspects of paediatric care (e.g. room, meals, personal issues, and family/visitors).
Ammentorp et al. 2006, Denmark	To investigate the determinants of parents' priorities and satisfaction in relation to paediatric inpatient care and to examine the relationship between fulfilment of expectations and satisfaction	253 parents in the first section and 170 parents in the second section parents of children admitted consecutively in a paediatric acute care inpatient department	Questionnaires consisted of six domain of quality: access to care and treatment, information and communication related to care and treatment, information related to practical conditions, doctors behaviour, nurses behaviour, access to service	Having confidence in the doctors, getting answers to questions about care and treatment, and being satisfied with nurses' and doctors' behaviour, were found to be determinants of having a satisfaction score above average. Waiting time was relatively weak determinant of being satisfied in general, although a short waiting time was one of the items given the highest priority score.
Pritchard & Howard 2006, UK	To involve parents in evaluating the services provided to their child while in inpatient on a children's surgical ward and to obtain to improve patient care, facilities and the clinical environment	100 parents of inpatients in a children's surgical ward	Questionnaire	A number of parents (60%) were dissatisfied with the noise level on the ward in contrast to the large number who asked for more televisions. 90 % of respondents were satisfied with the nursing care they received and 81 % of parents always felt involved in their child's care.
Lawoko 2007, Sweden	To review the published literature over the past 25 years on parental satisfaction with paediatric care of congenital heart disease (CHD) and well-being among the parents with the specific aim of 1) assessing the extent of psychosocial problems and grade of satisfaction with care and 2) modelling factors associated with satisfaction and well-being among the parents	80 publications /articles	Review	The research on satisfaction with care among PCCHD (parental satisfaction with care of congenital heart disease) is not conclusive, though there is considerable agreement that a substantial proportion of PCCHD may not receiving adequate information regarding the ill-child's condition, treatment and medical prognosis. Finally, based on the review of factors affecting satisfaction and well-being, a model is generated indicating that interactions between parental perception of CHD, psychosocial resources and social vulnerability may account for differences in well-being among PCCHD, which in turn may explain differences in satisfaction among them.

Appendix 4. Studies on the quality instruments in paediatric care.

Author, year, country	Purpose	Sample	Method	Main findings
Rifkin et al. 1988, USA	To describe the development of two instruments to measure aspects of 6-to 14 -year-old patients' perceptions of paediatric visits	75 children (6-14 yrs)	The Child Satisfaction Questionnaire (CSQ), Physician Attribute Checklist (PAC)	The CSQ a 19-item Likert scale is an easily administered and internally consistent instrument (alpha= .89). Negatively worded items included in the field trial of the CSQ were subsequently omitted because of poor comprehension by children under 12. This resulted in a 12-item scale with an alpha of .89. The PAC, a list of seven single-word descriptors, was moderately internally consistent (.70).
Budreau & Chase 1994, USA	To develop a family satisfaction questionnaire that would be multidisciplinary in its focus and would allow evaluation across hospital units and departments	7 parents in focus group, 4 parents in pilot study, 65 parents whose children taken care at a university hospital	Focus group to generate the items for the satisfaction questionnaire. Self –developed questionnaire (Pediatric Family Satisfaction Questionnaire PSFQ) including four aspects of care: technical-professional, education/information, relationship with family and relationship with the child in the four categories: hospital service and accommodations, nursing care, medical care and child life therapy; containing 67 total items	A focus group of parents assisted in item generation. A larger group of parents ranked items on a draft questionnaire. The final questionnaire Pediatric Family Satisfaction Questionnaire (PSFQ) included input from parents and nursing, medical, and child life departments of the hospital. The items of the PSFQ are: hospital service and accommodations (7), nursing care (12), medical care (11) and child life therapy (5).
McPherson et al. 2000, USA	To use classic survey methodology to develop a specific survey tool that can assess parent satisfaction with medical care in a paediatric intensive care setting	66 parents	Questionnaires	A four-stage process of item selection, item reduction, pretesting, and test analysis was used to create a 23 -item parent satisfaction survey that was statistically analyzed and developed specially for the PICU setting. This design yielded a survey with acceptable reliability, as demonstrated by a reliability coefficient of 0.8275. Test-retest reliability also showed good correlation of answers.
Moumtzoglou et al. 2000, Greece	The development and application of a questionnaire that eventually could be used as a management tool and a means of promoting the quality of care provided in P. & A. Kyriakou' Children's Hospital	240 parents	Questionnaire	The most important finding of the study, although normative statements cannot be made, appears to be signalling of low satisfaction with care. Satisfaction appears to be very low for the procedures of the hospital, low for the outpatient dimension and rather satisfactory for the inpatient dimension.
Schaffer et al. 2000, USA	To revise of a Parent Satisfaction Survey Based on the Parent Perspective	1045 parents of hospitalized children	The Parent Satisfaction Survey with 11 items and 3 open –ended questions. Revised Parent Satisfaction Survey based on parent responses including 4 main themes with 18 items and 4 open-ended questions	Five main themes were derived from the parents' responses were caring, communication, safety, physical environment and appreciation.
Varni et al. 2000, USA	To evaluate the reliability and factor structure of a new parent self-administered survey measure of satisfaction with health care for paediatric patients in haematology and oncology	113 parents	The Pediatric Hematology/Oncology Parent Satisfaction Survey (Par.SS)	The Par.SS demonstrated excellent internal consistency reliability, and factor analysis revealed 4 factors identified as General Satisfaction, Satisfaction With Staff Communication and Interaction Style, Satisfaction With Information Amount and Timeliness, and Satisfaction With the Staff's Provision of Emotional Support for the Patient and Parent. Parents reported high level of satisfaction across the 4 domains for the cohort tested.

Ygge & Arnetz 2001, Sweden	To apply and validate an adapted version of an existing patient questionnaire in a study of parental satisfaction with paediatric care in a university hospital	624 parents	The Parent Questionnaire consisted of eight domains: information on illness, information on routines, accessibility, medical treatment, care processes, staff attitudes, participation and staff work environment	The instrument demonstrated good reliability and validity. Reliability estimates for all eight indices were greater than 0.70 and consistent over time. Inter-index correlations were generally lower than 0.60, indicating index independence. Parents were most satisfied with staff attitudes, care processes and medical treatment. Parents' ratings were lowest for accessibility and staff work environment.
Bragadóttir & Reed 2002, USA	To evaluate parental satisfaction with hospital care in general paediatric units and to report on the psychometric testing of the Pediatric Family Satisfaction Questionnaire (PFSQ)	848 parents	the Pediatric Family Satisfaction Questionnaire (PFSQ)	Alpha for the total instrument was .83 based on 327 cases and 35 items. Factor analysis indicated two main factors, nursing care and medical care with a total of 30 items.
Latour et al. 2005, Netherlands	To assess the content and characteristics of satisfaction surveys for the development of a parent satisfaction questionnaire to improve clinical practice in paediatric intensive care	12 studies	Review	Ten original studies were identified using 10 different satisfaction surveys in paediatric, neonatal, or adult intensive care units or in general paediatric wards. All surveys counted a total of 248 questions. Six satisfaction questionnaires categorized the questions or statements in 21 different formulated domains. Most questionnaires showed sufficient results on reliability and validity.
Shaw et al. 2006b, UK	To develop scale to assess satisfaction with transitional heath care among adolescents with a chronic illness and their parents	301 adolescents (11-17 yrs), 286 parents	Questionnaire "Mind the Gap"	Factor analyses revealed a three-factor structure which explained 49,5 % and 56,1 % of the variation in adolescents and parent scores respectively. The internal consistency of each subscale ("management of environment", "provider characteristics" and "process issues") was indicated by Cronbach's alphas of 0.71,0.89 and 0.89 for adolescents, respectively, and 0.83, 0.91 and 0.92 for parents. This scale has wider potential for use with adolescents with other chronic illness in view of generic nature of transition.

Appendix 5

KESKUSTELUN ETENEMINEN

A) LAPSEN INFORMAATIO
* tutkimuksen tarkoitus, tulosten käyttö, piirtäminen, keskustelun eteneminen
* suostumuksen jälkeen, lupa nauhoittamiselle

B) LAPSEN TAUSTATIEDOT JA KESKUSTELUA KOSKEVAT TIEDOT

C) KESKUSTELUN ETENEMINEN JA PIIRTÄMINEN
Piirtäminen joko alussa tai lopussa lapsen valinnan mukaan

Toivesairaalasi (= millaista sairaalassa pitäisi olla?)
Kerro, mitä piirrät, olet piirtänyt
Miksi olet piirtänyt juuri ne asiat?

Kerro hoitajista / lääkäreistä, jotka ovat sinua hoitaneet?
Millaisen hoitajan / lääkärin haluaisit sinua hoitavan?
    Miksi juuri sellaisen?

Kerro, mitä hoitajat / lääkärit ovat tehneet sinulle tai sinun kanssasi?
Mitä olisit halunnut hoitajien / lääkärien tekevän kanssasi?
    Miksi juuri sitä?

Kerro, millaisessa huoneessa /osastolla olit hoidettavana?
    Keitä, mitä siellä oli, mitä teit siellä?
Millaista olisit halunnut siellä olevan?
    Keitä, mitä olisit halunnut siellä olevan?
    Mitä olisit halunnut siellä tehdä?
    Miksi?
Mikä oli ikävintä, kurjinta sairaalassa?
Lopuksi paljon, paljon kiitoksia, osasit hyvin vastata, hienoa, kerroit paljon sellaista, mitä en tiennyt …. –vuotiaista.

Appendix 6. Lapsen taustatiedot ja keskustelua koskevat tiedot.

Lapsen taustatiedot

1. Lapsen tunnusnumero
2. Ikä
3. Sukupuoli
4. Diagnoosi, minkä takia hoidossa
5. Onko ollut aiemmin sairaalassa hoidettavana?
    a) kyllä
    b) ei
    c) ei tiedä

Keskustelutilannetta koskevat tiedot

6. Aika, pvm:
7. Kesto, min:
8. Vanhemmat mukana keskustelutilanteessa
    a) kyllä, ketä
    b) ei
9. Nauhoitettu
    a) kyllä
    b) ei, miksi

10. Paikka:

11. Paikan luonne: rauhallinen -- levoton, miksi

12. Keskeytykset x ________

13. Kuka, tai mikä keskeytyksen aiheutti:

14. Lapsen käyttäytyminen keskustelutilanteessa:
    a) keskittynyt ------------------------------ levoton
    b) avoin ------------------------------ jännittynyt
    c) muuta:
15. Lapsen nonverbaalinen viestintä (ilmeet, eleet, ääni):

16. Keskustelutilanteen arviointi / vuorovaikutus lapsen kanssa
    a) hyvä --- huono
    b) muuta

17. Piirtäminen, järjestys:

Appendix 7. Quality indicators used in the studies analysed.

* *normal = studies with children, *italics = studies with children and parents*, underlined = studies with parents

MAIN CATEGORY	SUBCATEGORIES	Author and year*
BACKGROUND	The person the form is completed by	Vandvik et al. 1990, Budreau & Chase 1994, Brown et al. 1995, Filani 2001, Bragadóttir & Reed 2002, Lawoko & Soares 2004
	Parent's gender	*Mah et al. 2006*, Thornton 1996, Price 1993, Callery & Luker 1996, Moumtzoglou et al. 2000, Filani 2001, Shields & King 2001, Contro et al. 2002, Cygan et al. 2002, Lawoko & Soares 2004, Ammentorp et al. 2005, 2006, Heller & Solomon 2005
	Parent's age	*Kvist et al. 1991, Simonian et al. 1993, Magaret et al. 2002, Mah et al. 2006*, Thornton 1996, McPherson et al. 2000, Moumtzoglou et al. 2000, Contro et al. 2002, Cygan et al. 2002, Lawoko & Soares 2004
	Marital status	*Mah et al. 2006, Shaw et al. 2006ab,* Thornton 1996, Bragadóttir 1999, Cygan et al. 2002, Lawoko & Soares 2004, Heller & Solomon 2005
	Educational level	*Kvist et al. 1991, Simonian et al. 1993, Mah et al. 2006, Shaw et al. 2006ab*, Thornton 1996, Marino & Ganser 1997, Homer et al. 1999, Stubblefield & Murray 1999, Marino & Marino 2000, Moumtzoglou et al. 2000, Contro et al. 2002, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Ammentorp et al. 2005, 2006
	Profession or/and employment	*Mah et al. 2006, Shaw et al. 2006ab*, Moumtzoglou et al. 2000, Cygan et al. 2002, Lawoko & Soares 2004
	Parent's race	*Mah et al. 2006*, McPherson et al. 2000, Contro et al. 2002, Cygan et al. 2002, Lawoko & Soares 2004
	Number of children in family	*Kvist et al. 1991, Simonian et al. 1993,* Heller & Solomon 2005
	Distance to hospital	Stubblefield & Murray 1999
	Incomes/insurance	Rifkin et al.1988, *Simonian et al.1993, Mah et al. 2006, Shaw et al. 2006ab,*Vandvik et al. 1990, Brown et al. 1995, Marino & Ganser 1997, Homer et al. 1999, Stubblefield & Murray 1999, McPherson et al. 2000, Contro et al. 2002, Cygan et al. 2002, Lawoko & Soares 2004
	Child's gender	Rifkin et al. 1988, Freed et al. 1998, Carney et al. 2003, Curtis et al. 2004, Schmidt et al. 2007, *Kvist et al. 1991, Simonian et al. 1993, Enskär et al.1997, Chesney et al. 2005, Mah et al. 2006, Shaw et al. 2006ab,*Vandvik et al. 1990, Brown et al. 1995, Thornton 1996, Glasper et al. 1999, Homer et al. 1999, Moumtzoglou et al. 2000, Ygge & Arnetz 2001, 2004, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Heller & Solomon 2005, Micheli & Clark 2005
	Child's race	Rifkin et al. 1988, Freed at al. 1998, Curtis et al. 2004, *Shaw et al. 2006ab,* Homer et al. 1999, Marino & Marino 2000, Co et al. 2003, Heller & Solomon 2005
	Child's age	Rifkin et al. 1988, Freed et al. 1998, Carney et al. 2003, Curtis et al. 2004, Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007, *Kvist et al. 1991, Simonian et al. 1993, Enskär et al.1997, Sartain et al. 2001, Magaret et al. 2002, Battrick & Glasper 2004, Chesney et al. 2005, Witchell & Lester 2005, Mah et al. 2006, Shaw et al. 2006ab,* Vandvik et al. 1990, Dawson & Mogridge 1991, Price 1993, Davis 1995, Thornton 1996, Marino & Ganser 1997, Homer et al. 1999, Stubblefield & Murray 1999, Marino & Marino 2000, Moumtzoglou et al. 2000, Ygge & Arnetz 2001, 2004, Contro et al. 2002, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Heller & Solomon 2005, Micheli & Clark 2005
	Child's health status	Thornton 1996, Marino & Ganser 1997, Homer et al. 1999, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Ammentorp et al. 2005, 2006
	Reason for hospitalization / Diagnosis	Rifkin et al. 1988, Carney et al. 2003, Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007, *Kvist et al. 1991, Enskär et al.1997, Magaret et al. 2002, Mah et al. 2006,* Vandvik et al. 1990, Price 1993, Brown et al. 1995, Callery & Luker 1996, Stubblefield & Murray 1999, Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Ygge & Arnetz 2001, 2004, Contro et al. 2002, Cygan et al. 2002, Lawoko & Soares 2004, Ammentorp et al. 2005, 2006, Heller & Solomon 2005
	Manner of entering hospital (e.g. emergency)	*Battrick & Glasper 2004*, Dawson & Mogridge 1991, Budreau & Chase 1994, Marino & Ganser 1997, Moumtzoglou et al. 2000, Bragadóttir & Reed 2002, Aitken & Wiltshire 2005, Haines & Childs 2005, Micheli & Clark 2005
	Previous care at the same hospital	Brown et al. 1995, Freed at al. 1998, Coyne 2006b, Schmidt et al. 2007, *Chesney et al. 2005,* Vandvik et al. 1990, Dawson & Mogridge 1991, Budreau & Chase 1994, Brown et al. 1995, Thornton 1996, Glasper et al. 1999, McPherson et al. 2000, Moumtzoglou et al. 2000, Ygge & Arnetz 2001,2004, Cygan et al. 2002, Bragadóttir & Reed 2002, Ammentorp et al. 2005, 2006, Micheli & Clark 2005
	Same physician	Freed at al. 1998

MAIN CATEGORY	SUBCATEGORIES	Author and year*
	The number of days of hospitalization	Lindeke et al. 2006, *Kvist et al. 1991,* Vandvik et al. 1990, Dawson & Mogridge 1991, Price 1993, Budreau & Chase 1994, Marino & Ganser 1997, Homer et al. 1999, McPherson et al 2000, Moumtzoglou et al. 2000, Filani 2001, Bragadóttir & Reed 2002, Contro et al. 2002, Micheli & Clark 2005
	Ward	Curtis et al. 2004, Budreau & Chase 1994, Marino & Marino 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Bragadóttir & Reed 2002, Co et al. 2003, Haines & Childs 2005, Micheli & Clark 2005
	Place of further care	*Magaret et al. 2002*
	Procedures during hospitalization	*Magaret et al. 2002,* Lawoko & Soares 2004
	Pain management during hospitalization	*Magaret et al. 2002*
	Waiting times	*Magaret et al. 2002, Battrick & Glasper 2004*
	The number of other children at ward at the same time	*Magaret et al.2002*
	Parent's anxiety	Vandvik et al. 1990, Ygge & Arnetz 2001, 2004, Ammentorp et al. 2005, 2006
	Parent's place of living	Moumtzoglou et al. 2000,
CHARACTERISTICS		
	Humanity	Rifkin et al. 1988, Coyne 2006b, Lindeke et al. 2006, Schmidt et al. 2007,*Sartain et al. 2001, Battrick & Glasper 2004, Magaret et al. 2002, Chesney et al. 2005, Shaw et al.* 2006ab, Price 1993, Davis 1995, Stubblefield & Murray 1999, Budreau & Chase 1994, Brown et al. 1995, Marino & Ganser 1997, McPherson et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001,2004, Bragadóttir & Reed 2002, Contro et al. 2002, Stratton 2004, Ammentorp et al. 2005, Haines & Childs 2005, Micheli & Clark 2005
	Sense of Humour	Rifkin et al. 1988, Davis 1995, Haines & Childs 2005
	Trustworthiness	*Simonian et al.1993,* Price 1993, Marino & Ganser 1997,Ygge & Arnetz 2001, 2004, Contro et al. 2002, Co et al. 2003
	Competency/ technical-professional	Schmidt et al. 2007, *Kvist et al. 1991, Battrick & Glasper 2004, Chesney et al. 2005*, *Shaw 2006ab*, Budreau & Chase 1994, Brown et al. 1995, Davis 1995, Callery & Luker 1996, Thornton 1996, Homer et al. 1999, Marino & Marino 2000, Schaffer et al. 2000, Filani 2001, Shields & King 2001, Ygge & Arnetz 2001, 2004, Bragadóttir & Reed 2002, Contro et al. 2002, Cygan et al. 2002, Stratton 2004, Haines & Childs 2005, Micheli & Clark 2005
	Colourful clothes	Glasper et al. 1999,
	Recognizability	Brown et al. 1995, Marino & Ganser 1997, Glasper et al. 1999, Stubblefield & Murray 1999, Filani 2001, Heller & Solomon 2005, Pritchard & Howard 2006
	Age	Brown et al. 1995
NURSING ACTIVITIES		
	Entertainment	Schmidt et al. 2007, *Chesney et al. 2005*
	Education	Rifkin et al. 1988, Freed at al. 1998, al. Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007, *Simonian et al. 1993, Kvist et al. 1991, Sartain et al. 2001, Magaret et al. 2002, Battrick & Glasper 2004, Chesney et al. 2005, Witchell & Lester 2005, Mah et al. 2006*, Vandvik et al. 1990, Dawson & Mogridge 1991, Budreau & Chase 1994, Brown et al. 1995, Davis 1995, Thornton 1996, Marino & Ganser 1997, Homer et al. 1999, Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Shields & King 2001, Ygge & Arnetz 2001, 2004, Bragadóttir & Reed 2002, Contro et al. 2002, Cygan et al. 2002,Co et al. 2003, Lawoko & Soares 2004, Stratton 2004, Aitken & Wiltshire 2005, Haines & Childs 2005, Ammentorp et al. 2005, 2006, Heller & Solomon 2005, Micheli & Clark 2005
	Caring	Lindeke et al. 2006, *Chesney et al. 2005, Mah et al. 2006,* Dawson & Mogridge 1991, Brown et al. 1995, Marino & Ganser 1997, Glasper et al. 1999, Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, 2004, Cygan et al. 2002, Lawoko & Soares 2004, Stratton 2004, Ammentorp et al. 2005, 2006, Haines & Childs 2005, Heller & Solomon 2005
	Respect and communication	Rifkin et al. 1988, Freed at al. 1998, Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007, *Simonian et al. 1993, Enskär et al.1997, Chesney et al. 2005, Mah et al. 2006, Shaw et al. 2006ab,* Price 1993, Budreau & Chase 1994, Brown et al. 1995, Thornton 1996, Homer et al. 1999, Stubblefield & Murray 1999, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, 2004, Bragadóttir & Reed 2002, Cygan et al. 2002, Lawoko & Soares 2004, Stratton 2004, Haines & Childs 2005, Heller & Solomon 2005, Micheli & Clark 2005, Pritchard & Howard 2006

MAIN CATEGORY	SUBCATEGORIES	Author and year*
	Safety	Schmidt et al. 2007, *Kvist et al. 1991, Magaret et al. 2002,* Davis 1995, Marino & Marino 2000, McPherson et al. 2000, Varni et al. 2000, Stratton 2004, Ammentorp et al. 2005, 2006
	Physical care and treatment	Carney et al. 2003, Lindeke et al. 2006, Schmidt et al. 2007, *Kvist et al. 1991, Enskär et al.1997, Magaret et al. 2002, Battrick & Glasper 2004, Chesney et al. 2005,* Vandvik et al. 1990, Dawson & Mogridge 1991, Budreau & Chase 1994, Brown et al.1995, Davis 1995, Thornton 1996, Marino & Ganser 1997, Homer et al. 1999, Marino & Marino 2000, McPherson et al. 2000, Moumtzoglou et al. 2000, Schaffer et al. 2000, Varni et al. 2000, Filani 2001, Ygge & Arnetz 2001, 2004, Bragadóttir & Reed 2002, Cygan et al. 2002, Co et al. 2003, Lawoko & Soares 2004, Ammentorp et al. 2005, 2006, Micheli & Clark 2005
	Support initiative	*Chesney et al. 2005, Mah et al. 2006, Shaw et al. 2006ab*
	Parents' participation in care	Carney et al. 2003, *Kvist et al. 1991, Enskär et al.1997, Witchell & Lester 2005, Shaw et al. 2006ab,* Price 1993, Budreau & Chase 1994, Brown et al. 1995, Marino & Ganser 1997, Homer et al. 1999, Stubblefield & Murray 1999, Marino & Marino 2000, Varni et al. 2000, Ygge & Arnetz 2001, 2004, Bragadóttir & Reed 2002, Cygan et al. 2002, Co et al. 2003, Stratton 2004, Ammentorp et al. 2005, 2006, Haines & Childs 2005, Micheli & Clark 2005, Pritchard & Howard 2006
	Continuity	Curtis et al. 2004, *Kvist et al. 1991, Shaw et al. 2006ab,* Marino & Ganser 1997, Stubblefield & Murray 1999, Varni et al. 2000, Contro et al. 2002, Co et al. 2003, Haines & Childs 2005, Heller & Solomon 2005
	Co-operation	*Shaw et al. 2006ab,* Marino & Ganser 1997, Stubblefield & Murray 1999, McPherson et al. 2000, Moumtzoglou et al. 2000, Co et al. 2003, Haines & Childs 2005, Heller & Solomon 2005
	Hospital discharge planning	Homer et al. 1999, Haines & Childs 2005, Micheli & Clark 2005
ENVIRONMENT		
Physical		
	Hospital building and environment	Glasper et al. 1999
	Patient rooms - cleanliness - appearance - decoration	Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, *Battrick & Glasper 2004,Shaw et al. 2006ab,* Vandvik et al. 1990, Dawson & Mogridge 1991, Budreau & Chase 1994, Brown et al. 1995, Glasper et al. 1999, McPherson et al.2000, Schaffer et al. 2000, Filani 2001, Bragadóttir & Reed 2002, Cygan et al. 2002, Aitken & Wiltshire 2005, Haines & Childs 2005, Micheli & Clark 2005, Pritchard & Howard 2006
	Entertainment facilities	Carney et al. 2003, Curtis et al. 2004, Lindeke et al. 2006, Schmidt et al. 2007, *Enskär et al.1997, Sartain et al. 2001, Battrick & Glasper 2004, Witchell & Lester 2005, Mah et al. 2006, Shaw et al. 2006ab,* Vandvik et al. 1990 Budreau & Chase 1994, Brown et al. 1995, Glasper et al. 1999, Schaffer et al. 2000, Bragadóttir & Reed 2002, Aitken & Wiltshire 2005, Ammentorp et al. 2005, 2006, Haines & Childs 2005, Micheli & Clark 2005, Pritchard & Howard 2006
Social		
	Privacy	Curtis et al. 2004, Lindeke et al. 2006, *Battrick & Glasper 2004, Shaw et al. 2006ab,* Budreau & Chase 1994, Brown et al. 1995, McPherson et al. 2000, Schaffer et al. 2000, Filani 2001, Bragadóttir & Reed 2002, Aitken & Wiltshire 2005, Haines & Childs 2005, Micheli & Clark 2005
	Parents and relatives	
	Activities	
	- Safety	Carney et al. 2003, Coyne 2006b, Lindeke et al. 2006, *Kvist et al. 1991,* Callery & Luker 1996
	- Entertainment	Price 1993, Callery & Luker 1996
	- Caring	Coyne 2006b, *Kvist et al. 1991,* Callery & Luker 1996
	Friends and other patients	*Battrick & Glasper 2004*
	Activities	
	- Entertainment	Carney et al. 2003, *Sartain et al. 2001, Shaw et al. 2006ab*
Emotional	Sense of security	*Kvist et al. 1991, Chesney et al. 2005,* Davis 1995, Bragadóttir 1999, Schaffer et al. 2000, Micheli & Clark 2005
Food		Curtis et al. 2004, Lindeke et al. 2006, *Battrick & Glasper 2004,* Filani 2001, Ammentorp et al. 2005, 2006, Micheli & Clark 2005
Care resources	Access to care, waiting	*Kvist et al. 1991, Chesney et al. 2005,* Brown et al. 1995, Davis 1995, Ygge & Arnetz 2001, 2004, Lawoko & Soares 2004, Ammentorp et al. 2005,2006, Micheli & Clark 2005
	Availability of care	Marino & Ganser 1997, Cygan et al. 2002

Appendix 8

Vastaa kysymyksiin laittamalle rasti (X) sopivaan vaihtoehtoon tai kirjoita vastaus viivalle.

1. Olen
    1. tyttö
    2. poika
2. Olen
    1. 7 vuotta vanha
    2. 8 vuotta vanha
    3. 9 vuotta vanha
    4. 10 vuotta vanha
    5. 11 vuotta vanha

3. Tulin sairaalaan
    1. niin, että tuloni sairaalaan oli etukäteen sovittu
    2. niin, että tulin äkkiä kipeäksi/loukkasin itseni

4. Olen hoidossa tässä sairaalassa, koska minulla on ________________________
____.

5. Olen nyt ollut sairaalassa
    1. 1 yön
    2. 2 yötä
    3. 3 yötä
    4. 4 yötä
    5. enemmän kuin 5 yötä

6. Minua on hoidettu huoneessa,
    1. jossa vain minä olen ollut potilaana
    2. jossa on ollut myös muita potilaana olevia lapsia

7. Olen ennen ollut sairaalassa yötä
    1. Kyllä
    2. En
    3. En tiedä

8. Vanhempani ovat olleet kanssani sairaalassa
    1. kellon ympäri eli yötä päivää
    2. koko ajan paitsi yöllä
    3. muutaman tunnin päivässä
    4. noin tunnin päivässä
    5. vain, kun tulin sairaalaan ja pääsen kotiin

9. Minulla on ollut sairaalassa oma hoitaja, joka on hoitanut minua
    1. Kyllä
    2. Ei
    3. En tiedä

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Millaiset hoitajat Sinua ovat sairaalassa hoitaneet?

Laita rasti X iloiseen naamaan ☺, jos olet sitä mieltä, että hoitajat ovat aina olleet esimerkiksi kivoja.

Laita rasti X totiseen naamaan 😐, jos hoitajat ovat joskus olleet esimerkiksi kivoja.

Laita rasti X surulliseen naama ☹, jos hoitajat eivät koskaan ole olleet esimerkiksi kivoja.

Oikeaa tai väärä vastausta ei ole. Vastaa juuri niin kuin asiat Sinun mielestäsi ovat. Vastaa jokaiseen kohtaan.

Hoitajat ovat olleet	AINA ☺	JOSKUS 😐	EI KOSKAAN ☹
10. kivoja	☺	😐	☹
11. vihaisia	☺	😐	☹
12. auttavaisia	☺	😐	☹
13. kiireisiä	☺	😐	☹
14. kohteliaita	☺	😐	☹
15. hyviä hoitamaan lapsia	☺	😐	☹
16. iloisia	☺	😐	☹
17. tylsiä	☺	😐	☹
18. rehellisiä	☺	😐	☹
19. luotettavia	☺	😐	☹

20. Minusta hoitajilla pitäisi olla
    1. valkoinen työpuku
    2. värikäs työpuku
    3. värillä ei ole väliä

21. Minua hoitaneilla hoitajilla on ollut
    1. valkoinen työpuku
    2. värikäs työpuku

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Seuraavassa on lista erilaisista hoitajien tehtävistä sairaalassa. Nyt Sinun pitäisi kertoa, miten hoitajat ovat hoitaneet Sinua.
Laita rasti X iloiseen naamaan ☺, jos olet sitä mieltä, että hoitajat ovat aina toimineet kanssasi näin.
Laita rasti X totiseen naamaan 😐, jos hoitajat ovat joskus toimineet kanssasi näin.
Laita rasti X surulliseen naama ☹, jos hoitajat eivät koskaan ole toimineet kanssasi näin.

Oikeaa tai väärää vastausta ei ole. Vastaa juuri niin kuin asiat Sinun mielestäsi ovat. Vastaa jokaiseen kohtaan.

	ASIAN TOTEUTUMINEN		
Hoitajat ovat	AINA ☺	JOSKUS 😐	EI KOSKAAN ☹
22. leikkineet kanssani	☺	😐	☹
23. katsoneet tv:tä ja/tai videota kanssani	☺	😐	☹
24. pitäneet hyvää huolta minusta	☺	😐	☹
25. hoitaneet minua niin, että olen joutunut olemaan esimerkiksi alasti huoneessa, jossa on muita lapsia tai vanhempia	☺	😐	☹
26. kuunnelleet minua	☺	😐	☹
27. ottaneet mielipiteeni huomioon	☺	😐	☹
28. ymmärtäneet, mitä olen yrittänyt sanoa	☺	😐	☹
29. olleet kanssani, jos olen halunnut	☺	😐	☹
30. lohduttaneet minua	☺	😐	☹
31. vähentäneet pelkojani	☺	😐	☹
32. hoitaneet kipujani	☺	😐	☹
33. auttaneet minua syömisessä	☺	😐	☹

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Hoitajat ovat	ASIAN TOTEUTUMINEN		
	AINA ☺	JOSKUS 😐	EI KOSKAAN ☹
34. auttaneet minua pesuissa	☺	😐	☹
35. auttaneet minua vessalla käynneissä	☺	😐	☹
36. seuranneet vointiani tarkasti	☺	😐	☹
37. kertoneet minulle sairaalan päivästä eli mitä minulle milloinkin tapahtuu	☺	😐	☹
38. antaneet minulle riittävästi tietoa, miksi olen sairaalassa	☺	😐	☹
39. antaneet minulle riittävästi tietoa, miten sairauttani hoidetaan	☺	😐	☹
40. antaneet minulle riittävästi tietoa lääkkeistäni	☺	😐	☹
41. antaneet minulle riittävästi tietoa, mitä voin syödä ja juoda sairaalassa	☺	😐	☹
42. antaneet minulle riittävästi tietoa, miten ja missä voin liikkua sairaalassa	☺	😐	☹
43. antaneet riittävästi tietoa minulle tehtävistä toimenpiteistä (kuten verinäytteen ottamisesta tai röntgen kuvan ottamisesta)	☺	😐	☹
44. antaneet riittävästi tietoa, miten hoidan itseäni kotona, kun pääsen sairaalasta kotiin	☺	😐	☹
45. kertoneet, milloin voin mennä kouluun	☺	😐	☹
46. kertoneet, milloin voin osallistua harrastuksiini	☺	😐	☹
47. selittäneet asiat niin, että olen ne ymmärtänyt	☺	😐	☹
48. kertoneet, mitä voin itse tehdä sairaalassa	☺	😐	☹
49. hoitaneet minua yhdessä vanhempien kanssa	☺	😐	☹
50. antaneet vanhempieni olla kanssani	☺	😐	☹

Appendix 8

Minkälainen tämä sairaala on Sinun mielestä ollut?

Laita rasti X

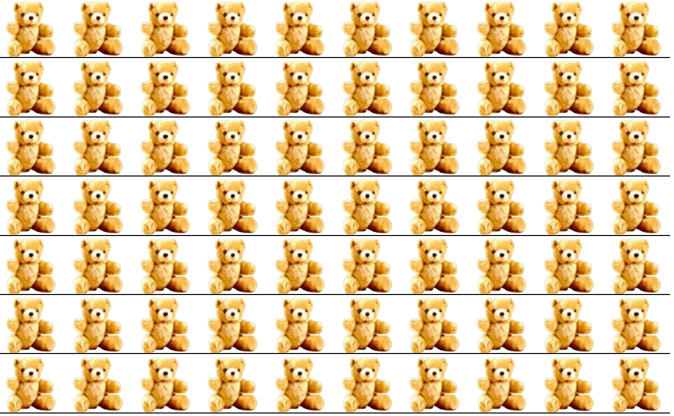
kaikkien nallejen päälle, jos olet täysin samaa mieltä asiasta.

Laita rasti X

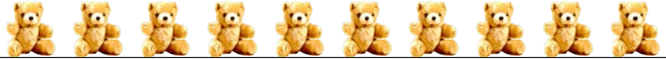
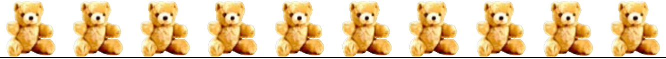
vain yhden nallen päälle, jos olet täysin eri mieltä asiasta.

Mitä enemmän rastitat nalleja, sitä enemmän olet samaa mieltä asiasta.
Mitä vähemmän rastitat nalleja, sitä vähemmän olet samaa mieltä asiasta.
Oikeaa tai väärää vastausta ei ole. Vastaa juuri niin kuin asiat Sinun mielestäsi ovat. Vastaa jokaiseen kohtaan.

51. Sairaalassa on ollut riittävästi tekemistä
52. Olen lukenut sairaalassa kirjoja ja lehtiä
53. Olen katsonut sairaalassa TV:tä ja videoita
54. Olen pelannut sairaalassa erilaisia pelejä
55. Olen askarrellut sairaalassa
56. Olen leikkinyt erilaisilla leluilla
57. Olen katsellut sairaalan ikkunoista ulos



58. Olen voinut olla yksin sairaalassa, jos olen halunnut	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
59. Vanhempani ovat voineet olla riittävästi kanssani sairaalassa	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
60. Sisaret ja veljeni ovat voineet olla riittävästi kanssani sairaalassa	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
61. Isovanhempani (mamma ja pappa) ovat voineet olla riittävästi kanssani sairaalassa	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
62. Sairaalassa on tarpeeksi tilaa vanhemmilleni esimerkiksi olla yötä kanssani	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
63. Sairaalassa on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
64. Toisista potilaina olevista lapsista on ollut minulle seuraa	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
65. Huoneessani on ollut sopiva määrä muita lapsia	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
66. Sairaalassa on ollut kodikasta ja viihtyisää	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
67. Sairaalan huonekalut on suunniteltu lapsille sopiviksi	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
68. Sairaalassa on ollut siistiä	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
69. Sairaalassa on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
70. Sairaalassa olen tuntenut oloni turvalliseksi	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸
71. Sairaalan muut potilaana olevat lapset ovat pelottaneet minua	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸	🧸

72. Sairaalassa on ollut pelottavia koneita ja laitteita	
73. Olen pelännyt sairaalan hoitajia ja lääkäreitä	
74. Vanhempieni mukanaolo sairaalassa on vähentänyt pelkojani	
75.Sairaalan ruoka on ollut hyvää	

76. Minun mielestä kivointa sairaalassa on ollut

____

____

____

77. Minun mielestä tylsintä sairaalassa on ollut

____

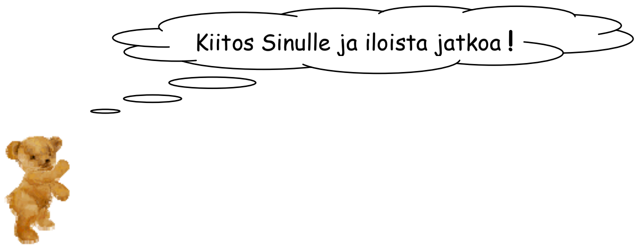
____

____

78. Auttoivatko vanhempasi tähän vihkoon vastaamisessa?
- a) Ei
- b) Kyllä, jos vastasit kyllä niin, miten he Sinua auttoivat?
  - a) lukivat kysymykset minulle
  - b) merkitsivät vastaukseni
  - c) selittivät minulle kysymyksiä, jos en niitä ymmärtänyt
  - d) muulla tavoin, miten?____

79. Piirrä ohessa olevaan potilashuoneeseen ihmisiä ja tavaroita, jotka kuuluvat lasten hyvään hoitamiseen. Jos haluat voit kirjoittaa kuvan alle, mitä olet piirtänyt.

tähän tulee tyhjä potilashuone sisältä päin, jossa piirrettynä vain ikkuna.



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Hei!

Olen kiinnostunut siitä, mitä mieltä kouluikäiset lapset ovat sairaalahoidosta Suomessa eli juuri Sinun mielipiteesi on tärkeä asian selvittämiseksi.

- Vastaa kysymyksiin rehellisesti, juuri niin kuin itse ajattelet.
- Oikeita tai vääriä vastauksia ei ole olemassa.
- Vastaa joka kohtaan.
- Nimeäsi Sinun ei tarvitse laittaa vihkoon.
- Kun olet vastannut vihkoon, laita se kirjekuoreeseen ja sulje se.
- Anna kirjekuori hoitajille ennen kuin lähdet sairaalasta kotiin, niin he palauttavat sen edelleen minulle.
- Hoitajat antavat sinulle pienen palkkion, kun olet vastannut.
- Vastauksesi käsittelen luottamuksellisesti, kukaan ei tiedä mikä on juuri Sinun täyttämäsi vihko.

Vastauksiasi tulen käyttämään tutkimuksessani, jota teen Turun yliopiston hoitotieteen laitoksella.

Vaikka vastaaminen on vapaaehtoista, toivon Sinun vastaavan, koska pidän Sinun mielipidettäsi tärkeänä tutkimukseni kannalta.

Kiitos Sinulle!

Tiina Pelander
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Vastaa kysymyksiin laittamalla rasti (X) sopivaan vaihtoehtoon tai kirjoita vastaus viivalle.

1. Olen
   - a) tyttö
   - b) poika

2. Olen
   - a) 7 vuotta vanha
   - b) 8 vuotta vanha
   - c) 9 vuotta vanha
   - d) 10 vuotta vanha
   - e) 11 vuotta vanha

3. Tulin sairaalaan,
   - a) koska siitä oli etukäteen sovittu
   - b) koska loukkasin itseni
   - c) koska tulin äkkiä kipeäksi

4. Olen nyt sairaalassa, koska minulla on ____.

5. Olen nyt ollut sairaalassa
   - a) 1 yön
   - b) 2 yötä
   - c) 3 yötä
   - d) 4 yötä
   - e) enemmän kuin 5 yötä

jatkuu

6. Sairaalassa olen ollut huoneessa,
    a) jossa olen ollut potilaana yksin
    b) jossa on ollut myös muita potilaana olevia lapsia

7. Olen ennenkin ollut joskus sairaalassa yötä
    a) Kyllä
    b) En
    c) En tiedä
    d) En muista

8. Vanhempani ovat olleet kanssani sairaalassa
    a) koko ajan
    b) päivällä, mutta ei yöllä
    c) muutaman tunnin päivällä
    d) kun tulin sairaalaan ja pääsen kotiin

9. Minulla on ollut sairaalassa oma hoitaja
    a) Kyllä
    b) Ei
    c) En tiedä

jatkuu

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Millaiset hoitajat Sinua ovat sairaalassa hoitaneet?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina olleet esimerkiksi kivoja.

Rastita 😐 naama, jos hoitajat mielestäsi ovat joskus olleet esimerkiksi kivoja.

Rastita ☹ naama, jos hoitajat mielestäsi eivät koskaan ole olleet esimerkiksi kivoja.

Hoitajani ovat olleet	AINA	JOSKUS	EI KOSKAAN
10. kilttejä	☺	😐	☹
11. rauhallisia	☺	😐	☹
12. komentelevia	☺	😐	☹
13. kiireisiä	☺	😐	☹
14. kivoja	☺	😐	☹
15. ikäviä	☺	😐	☹
16. hauskoja	☺	😐	☹
17. pitkästyttäviä	☺	😐	☹
18. rehellisiä	☺	😐	☹
19. eivät ole pitäneet lupauksiaan	☺	😐	☹

20. Hoitajillani on ollut
    a) valkoiset vaatteet
    b) värikkäät vaatteet
    c) en muista millaiset vaatteet

jatkuu

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Seuraavassa on asioita, joita hoitajat tekevät sairaalassa. Mitä hoitajat ovat tehneet Sinun kanssasi?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina tehneet kanssasi näin.

Rastita 😐 naama, jos hoitajat ovat joskus tehneet kanssasi näin.

Rastita ☹ naama, jos hoitajat eivät koskaan ole tehneet kanssasi näin.

	ASIAN TOTEUTUMINEN		
Hoitajat ovat	AINA	JOSKUS	EI KOSKAAN
21. leikkineet kanssani	☺	😐	☹
22. katsoneet tv:tä ja/tai videota kanssani	☺	😐	☹
23. pitäneet hyvää huolta minusta	☺	😐	☹
24. hoitaneet minua niin, että toiset huoneessa olijat ovat nähneet minut ilman vaatteita	☺	😐	☹
25. kuunnelleet minua	☺	😐	☹
26. ottaneet mielipiteeni huomioon	☺	😐	☹
27. rohkaisseet minua	☺	😐	☹
28. lohduttaneet minua	☺	😐	☹
29. hoitaneet kipujani	☺	😐	☹
30. auttaneet minua syömisessä	☺	😐	☹
31. auttaneet minua pesuissa	☺	😐	☹
32. auttaneet minua vessassa käynneissä	☺	😐	☹
33. kertoneet, mitä saan itse tehdä sairaalassa	☺	😐	☹
34. ovat antaneet minun itse osallistua omaan hoitooni	☺	😐	☹
35. hoitaneet minua yhdessä vanhempien kanssa	☺	😐	☹
36. selittäneet asiat niin, että olen ne ymmärtänyt	☺	😐	☹

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Mitä asioita hoitajat ovat Sinulle kertoneet?

Hoitajat ovat kertoneet minulle **tarpeeksi**	AINA	JOSKUS	EI KOSKAAN
37. sairaalan päivästä	☺	😐	☹
38. etukäteen kaikesta, mitä minulle tapahtuu	☺	😐	☹
39. miksi olen sairaalassa	☺	😐	☹
40. miten sairauttani hoidetaan	☺	😐	☹
41. lääkkeistäni	☺	😐	☹
42. mitä voin syödä ja juoda sairaalassa	☺	😐	☹
43. miten ja missä voin liikkua sairaalassa	☺	😐	☹
44. minulle tehtävistä toimenpiteistä (kuten verinäytteen tai röntgenkuvan ottamisesta)	☺	😐	☹
45. miten hoidan itseäni kotona, kun pääsen sairaalasta kotiin	☺	😐	☹

jatkuu

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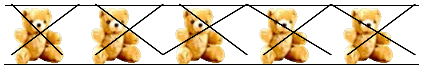
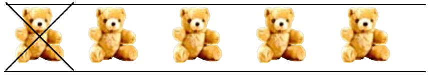
Seuraavassa on asioita sairaalasta, joiden paikkansa pitävyyttä arvioit rastittamalla nalleja.

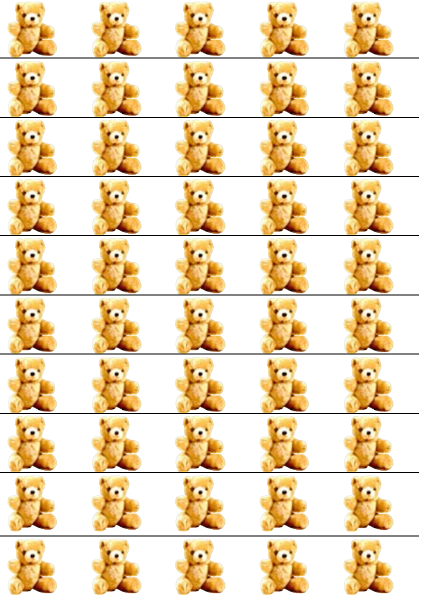
Rastita sitä enemmän nalleja, mitä enemmän asia pitää paikkaansa
eli olet asiasta samaa mieltä.



Rastita sitä vähemmän nalleja, mitä vähemmän asia pitää paikkaansa
eli olet asiasta eri mieltä.



46. Minulla on ollut sairaalassa tarpeeksi tekemistä
47. Olen lukenut kirjoja ja lehtiä
48. Olen katsonut TV:tä ja videoita
49. Olen pelannut erilaisia pelejä
50. Olen askarrellut
51. Olen leikkinyt leluilla
52. Olen voinut olla yksin sairaalassa, jos olen halunnut
53. Vanhempani ovat voineet olla tarpeeksi kanssani sairaalassa
54. Siskoni ja veljeni ovat voineet olla tarpeeksi kanssani sairaalassa
Laita rasti, jos sinulla ei ole siskoja tai veljiä ☐
55. Isovanhempani ovat voineet olla tarpeeksi kanssani sairaalassa
Laita rasti, jos sinulla ei ole isovanhempia ☐



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56. Äiti tai isä on voinut olla yötä kanssani sairaalassa

57. Sairaalassa on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa

58. Toisista potilaina olevista lapsista on ollut minulle seuraa

59. Toiset potilaana olevat lapset ovat häirinnet minua

60. Sairaalassa on ollut kodikasta ja viihtyisää

61. Sairaalan huonekalut ovat lapsille sopivia

62. Sairaalassa on ollut puhdasta

63. Sairaalassa on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen

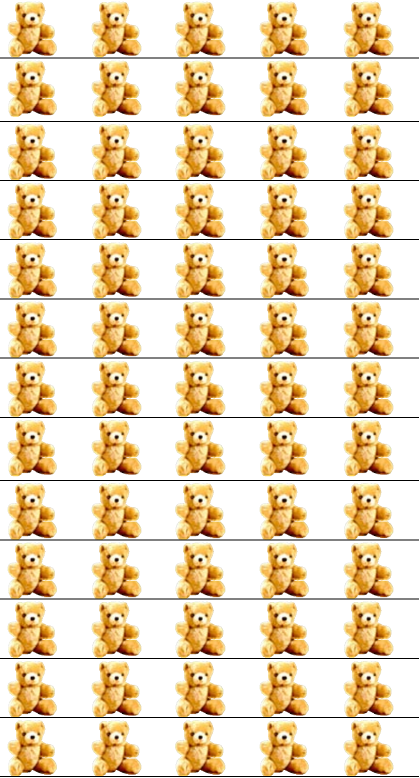
64. Olen pelännyt sairaalassa

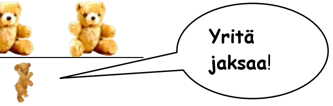
65. Olen pelännyt sairaalan laitteita ja koneita

66. Olen pelännyt sairaalassa potilaana olevia muita lapsia

67. Olen pelännyt yksinoloa

68. Olen pelännyt hoitajia ja lääkäreitä





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69. Minun mielestä kivointa sairaalassa on ollut

70. Minun mielestä ikävintä sairaalassa on ollut

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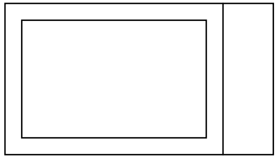
71. Piirrä sairaalahuone sellaiseksi, mitä mielestäsi siellä pitäisi olla, jotta lapset saisivat mahdollisimman hyvää hoitoa.
Voit kirjoittaa kuvan alle tai taakse itse, mitä olet piirtänyt tai pyytää vanhempiasi kirjoittamaan.



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Hienoa, että olet jaksanut vastata kaikkiin kysymyksiin. Kerro vielä, mitä mieltä olit vastaamisesta.

72. Oliko kysymyksiä
    - a) liian paljon
    - b) sopivasti
    - c) liian vähän

73. Miten hyvin jaksoit mielestäsi vastata kysymyksiin?
    - a) hyvin
    - b) melko hyvin
    - c) huonosti

74. Auttoivatko vanhempasi tähän vihkoon vastaamisessa?
    - a) Ei
    - b) Kyllä, jos vastasit kyllä niin, miten he Sinua auttoivat?
        - a) lukivat kysymykset minulle
        - b) merkitsivät vastaukseni
        - c) selittivät minulle kysymyksiä, jos en niitä ymmärtänyt
        - d) muulla tavoin, miten?____

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LASTEN OSASTOJEN HOITOHENKILÖKUNTA
- ASIANTUNTEMUSTANNE TARVITAAN LASTEN HOITOTYÖN KEHITTÄMISEKSI

Arvioitavana on lasten hoitotyön laadun mittari, joka on suunniteltu erityisesti kouluikäisille 7 – 11 -vuotiaille lapsille, jotka ovat sairaalassa vuodeosastohoidossa. Mittarin nimi on ”Minun hoitoni sairaalassa oli” –vihko. Mittari on siis tarkoitettu ja kehitetty nimenomaan lapsille. Mittari on kehitetty lasten hyvän hoidon odotusten pohjalta, jotka on saatu laadullisilla menetelmillä sekä aikaisemman kirjallisuuden perusteella. Tavoitteena on kehittää lapsille oma laadun arviointimittari, jota voitaisiin jatkossa käyttää käytännön lasten hoitotyön laadun arvioinnissa.

Mittarin arvioinnissa ja kehittämisessä tarvitsen nyt Teidän asiantuntemustanne. Toivon, että osastolla yhdessä arvioisitte mittarin soveltuvuutta lasten hoitotyön laadun arviointiin sekä sen soveltuvuutta juuri kouluikäisille lapsille. Ohessa on yksityiskohtaiset kyselyn vastausohjeet. Lukekaa ne huolellisesti ennen lomakkeen täyttämistä.

Vastaan mielelläni kysymyksiin,

Yhteistyöterveisin,

Tiina Pelander
ESH, THM, TtT-opiskelija
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24100 Salo
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E-mail: tiina.pelander@utu.fi

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ARVIOINTIOHJEET

Arvioitavana on lasten hoitotyön laatumittari, jonka nimi tällä hetkellä on ”Hoitoni sairaalassa oli” -vihko. Mittarissa on kolme luokkaa (hoitohenkilökunnan ominaisuudet, hoitotyön toiminnot, hoitotyön ympäristö), jotka sisältävät yhteensä 15 osiota. Kustakin osiosta on lisäksi esitetty osioon kuuluvat mittarin väittämät.

Tässä kyselyssä lasten laatu mittaria arvioidaan luokittain ja osioittain.

Luokka	Luokan nimi on kirjoitettu isoilla kirjaimilla ja tummennettu taulukon vasemmassa yläreunassa. Esimerkiksi luokka I **HOITOHENKILÖKUNNAN OMINAISUUDET**
Osio	Osiot ovat lomakkeen vasemmassa reunassa numeroituna 1 – 15 kirjoitettuna isoilla ja tummennetuilla kirjaimilla. Esimerkiksi osio 1 **INHIMILLISYYS**
Väittämä	Väittämät ovat lomakkeen vasemmassa reunassa numeroidun osion alla sisennettyinä ja pienillä kirjaimilla kirjoitettuna. Kukin osio sisältää 1- 12 sen sisältöä kuvaavaa väittämää. Esimerkiksi osion 1 ensimmäinen väittämä Hoitajat ovat olleet kilttejä.

I OSIOKOHTAINEN ARVIOINTI

Tarkastelkaa kutakin osiota erikseen. Osion alla on osion sisältöä kuvaavat väittämät
Kuhunkin osioon liittyen lomakkeessa on kuusi kysymystä. Kysymykset ja niiden vastausohjeet on esitetty seuraavassa yksityiskohtaisesti. Kyselylomakkeen yläreunassa on vain kysymyksen muistamista helpottavia avainsanoja. Vastauksenne voitte kirjoittaa kysymysten alle tai lomakkeen taakse numeroituna.

1. Miten tärkeä osio on hoitotyön laadussa?
    - Arvioikaa, miten tärkeä osion sisältämä asia on lapsen kannalta hoidon laadussa. Vastatkaa ympyröimällä mielipidettänne kuvaava vaihtoehto: Osion sisältämä asia on 1) ei tärkeä, 2) vähän tärkeä, 3) tärkeä, 4) erittäin tärkeä.
    - Halutessanne voitte perustella mielipiteenne.

2. Mittaako osio hoitotyön laatua?

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- Arvioikaa, onko kyseisen osion osoittama asia lasten hoitotyön laadun osoitin. Vastatkaa ympyröimällä joko 1) kyllä tai 2) ei
- Jos osio ei mielestänne mittaa hoitotyön laatua 2), perustelkaa mielipiteenne.

3. Kuuluuko osio tähän luokkaan?
    - Arvioikaa, kuuluko osio mielestänne tarkasteltavaan luokkaan. Vastatkaa ympyröimällä joko 1) kyllä tai 2) ei.
    - Jos osio ei mielestänne kuulu arvioitavaan luokkaan 2) perustelkaa mielipiteenne.
4. Mittaako joku muu osio samaa laatutekijää?
    - Tarkastelkaa, mittaako saman tai jonkun toisen luokan osio samaa asiaa. Vastatkaa ympyröimällä joko 1) kyllä tai 2) ei.
    - Jos joku muu osio mittaa samaa 2), perustelkaa mielipiteenne.
5. Onko osio selkeä?
    - Arvioikaa osion selkeyttä tarkastelemalla sen yksiselitteisyyttä ja ymmärrettävyyttä.
    - Vastatkaa ympyröimällä mielipidettänne kuvaava vaihtoehto: Osion sisältämä asia 1) ei ole selkeä, 2) vähän selkeä, 3) selkeä tai 4) erittäin selkeä.
    - Jos osio ei ole selkeä, perustelkaa mielipiteenne.
6. Onko osio konkreettinen?
    - Arvioikaa osion konkreettisuutta tarkastelemalla ilmaiseeko osio mittaamansa hoitotyön alueen niin konkreettisesti, että se on mitattavissa. Vastatkaa ympyröimällä mielipidettänne kuvaava vaihtoehto: Osion sisältämä asia on 1) ei konkreettinen 2) vähän konkreettinen, 3) konkreettinen 4) erittäin konkreettinen.
    - Jos osio ei ole konkreettinen, perustelkaa mielipiteenne.

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II LUOKITTAINEN ARVIOINTI

Yksittäisten osioiden lisäksi arvioidaan koko luokkaa. Tarkastelkaa yhtä luokkaa kerrallaan. Tutustukaa luokan nimeen ja sen sisällön määrittelyyn (osiot ja väittämät).

7. Mittaako luokka hoitotyön laatua?
    - Arvioikaa, onko kyseisen luokan osoittama asia eräs keskeinen hoitotyön laadun osoitin. Vastatkaa ympyröimällä 1) kyllä tai 2) ei.
    - Jos luokka ei mittaa hoitotyön laatua 2), perustelkaa mielipiteenne.

8. Miten hyvin, tämän luokan osiot kattavat luokan tarkoittaman hoitotyön alueen?
    - Tarkastelkaa, miten hyvin luokan osiot kattavat luokan nimen osoittaman sisällön. Vastatkaa ympyröimällä mielipidettänne kuvaava vaihtoehto:1) ei ollenkaan, 2) huonosti, 3) tyydyttävästi tai 4) hyvin.
    - Jos luokan osiot eivät kata luokan tarkoittamaa hoitotyön aluetta, perustelkaa mielipiteenne.

9. Mitkä alueet puuttuvat luokasta?
    - Lisätkää asioita, jotka luokasta mielestänne puuttuvat.

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Vastatkaa ympyröimällä osaston henkilökunnan valitsema vaihtoehto ja perustelkaa tarvittaessa vastauksenne kysymyksen alle tai paperin kääntöpuolelle. Yksityiskohtaiset vastusohjeet löydätte erillisestä ohjeesta.

1. Sairaala nimi

____

2. Osasto

____

3. Onko osastollanne kokemusta hoitotyön laadun kehittämisestä?

   1) Ei
   2) Kyllä, minkälaista ______________________________________

____

4. Onko osastollanne kokemusta hoitotyön laadun kehittämisestä lasten näkökulmasta?

   1) Ei
   2) Kyllä, minkälaista ______________________________________

____

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LUOKKA I **HOITOHENKILÖKUNNAN OMINAISUUDET** **OSIOT ja esimerkit**	1.MITEN TÄRKEÄ? 1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	2.MITTAA-KO OSIO LAATUA? 1. kyllä 2. ei	3.KUULUU-KO OSIO TÄHÄN LUOKKAAN ? 1. kyllä 2. ei	4. MITTAA-KO JOKU MUU OSIO SAMAA? 1. kyllä 2. ei	5. SELKEYS 1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	6.KONKREETTISUUS 1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
1.INHIMILLISYYS Hoitajat ovat olleet kilttejä, rauhallisia, komentelevia kiireisiä, kivoja ikäviä.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
2. HUUMORINTAJUISUUS Hoitajat ovat olleet hauskoja, pitkästyttäviä.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
3. LUOTETTAVUUS Hoitajat ovat olleet rehellisiä, eivät ole pitäneet lupauksiaan.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
4. ULKOINEN OLEMUS Hoitajillani on ollut valkoiset vaatteet, värikkäät vaatteet tai en muista millaiset vaatteet.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

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7. Mittaako luokka ”hoitotyöntekijöiden ominaisuudet” laatua?

1) Kyllä
2) Ei, perustelu ____

____

8. Miten hyvin tämän luokan ” hoitotyöntekijöiden ominaisuudet” osiot kattavat luokan tarkoittaman hoitotyön alueen?

1) Hyvin
2) Tyydyttävästi
3) Huonosti
4) Ei ollenkaan, perustelu ____

____

9. Mitkä keskeiset alueet puuttuvat luokasta ” hoitotyöntekijöiden ominaisuudet”?______________________

____

LUOKKA II HOITOTYÖN TOIMINNOT OSIOT ja esimerkit	1.MITEN TÄRKEÄ? 1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	2.MITTAA-KO OSIO LAATUA? 1. kyllä 2. ei	3. KUULUU-KO OSIO TÄHÄN LUOKKAAN? 1. kyllä 2. ei	4. MITTAA-KO JOKU MUU OSIO SAMAA? 1. kyllä 2. ei	5. SELKEYS 1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	6. KONKREETTISUUS 1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
5. VIIHDYTTÄMINEN Hoitajat ovat leikkineet kanssani. Hoitajat ovat katsoneet tv:tä ja /tai videota kanssani.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
6. AUTTAMINEN JA HUOLENPITO Hoitajat ovat pitäneet hyvää huolta minusta. Hoitajat ovat hoitanet minua niin, että toiset huoneessa olijat ovat nähneet minut ilman vaatteita.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
7. KUNNIOITTAMINEN JA VUOROVAIKUTUS Hoitajat ovat kuunnelleet minua. Hoitajat ovat ottaneet mielipiteeni huomioon.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
8. TURVALLISUUDEN TUOMINEN Hoitajat ovat rohkaisseet minua. Hoitajat ovat lohduttaneet minua.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
9. FYYSINEN HOITAMINEN Hoitajat ovat hoitaneet kipujani. Hoitajat ovat auttaneet minua syömisessä. Hoitajat ovat auttaneet minua pesuissa. Hoitajat ovat auttanet minua vessassa käynneissä.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

10. OMATOIMISUUDEN TUKEMINEN Hoitajat ovat kertoneet, mitä saan itse tehdä sairaalassa. Hoitajat ovat antaneet minun osallistua omaan hoitooni.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
11. VANHEMPIEN OSALLISTUMINEN HOITOON Hoitajat ovat hoitaneet minua yhdessä vanhempieni kanssa.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
12. OHJAAMINEN JA TIEDON ANTAMINEN Hoitajat ovat selittäneet asiat niin, että olen ne ymmärtänyt. Hoitajat ovat kertoneet minulle tarpeeksi sairaalan päivästä, etukäteen kaikesta, mitä minulle tapahtuu, miksi olen sairaalassa, miten sairauttani hoidetaan, lääkkeistäni, mitä voin syödä ja juoda sairaalassa, miten ja missä voin liikkua sairaalassa, minulle tehtävistä toimenpiteistä (kuten verinäytteen tai röntgenkuvan ottamisesta), miten hoidan itseäni kotona, kun pääsen sairaalasta kotiin.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

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10. Mittaako luokka ”hoitotyön toiminnot” laatua?
    1) Kyllä
    2) Ei, perustelu ____
    ____

11. Miten hyvin tämän luokan ” hoitotyön toiminnot” osiot kattavat luokan tarkoittaman hoitotyön alueen?
    1) Hyvin
    2) Tyydyttävästi
    3) Huonosti
    4) Ei ollenkaan, perustelu ____
    ____

12. Mitkä keskeiset alueet puuttuvat luokasta ” hoitotyön toiminnot”?____________________________
____

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LUOKKA III HOITOTYÖN YMPÄRISTÖ OSIOT ja esimerkit	1.MITEN TÄRKEÄ? 1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	2. MITTAAKO OSIO LAATUA? 1. kyllä 2. ei	3. KUULUUKO OSIO TÄHÄN LUOKKAAN? 1. kyllä 2. ei	4. MITTAAKO JOKU MUU OSIO SAMAA? 1. kyllä 2. ei	5. SELKEYS 1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	6. KONKREETTISUUS 1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
13. SOSIAALINEN YMPÄRISTÖ Minulla on ollut sairaalassa tarpeeksi tekemistä. Olen lukenut kirjoja ja lehtiä. Olen katsonut TV:tä ja videoita. Olen pelannut erilaisia pelejä. Olen askarrellut sairaalassa. Olen leikkinyt leluilla. Olen voinut olla yksin sairaalassa, jos olen halunnut. Vanhempani ovat voineet olla tarpeeksi kanssani sairaalassa. Sisaret ja veljeni ovat voineet olla tarpeeksi kanssani sairaalassa. Isovanhempani ovat voineet olla tarpeeksi kanssani sairaalassa. Toisista potilaina olevista lapsista on ollut minulle seuraa. Toiset potilaana olevat lapset ovat häirinneet minua.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
14. FYYSINEN YMPÄRISTÖ Äiti tai isä on voinut olla yötä kanssani sairaalassa. Sairaalassa on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa. Sairaalassa on ollut kodikasta ja viihtyisää. Sairaalan huonekalut ovat lapsille sopivia. Sairaalassa on ollut puhdasta.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

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Sairaalassa on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen.						
15. PSYYKKINEN YMPÄRISTÖ Olen pelännyt sairaalassa. Olen pelännyt sairaalan laitteita ja koneita. Olen pelännyt sairaalassa potilaana olevia muita lapsia. Olen pelännyt yksinoloa. Olen pelännyt sairaalan hoitajia ja lääkäreitä.	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

13. Mittaako luokka ”hoitotyön ympäristö” laatua?

1) Kyllä
2) Ei, perustelu ____

____

14. Miten hyvin tämän luokan ” hoitotyön ympäristö” osiot kattavat luokan tarkoittaman hoitotyön alueen?

1) Hyvin
2) Tyydyttävästi
3) Huonosti
4) Ei ollenkaan, perustelu ____

____

15. Mitkä keskeiset alueet puuttuvat luokasta ” hoitotyön ympäristö”?______________________

____

SUURKIITOKSET TYÖSTÄNNE!

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Hei!

Olen kiinnostunut siitä, mitä mieltä kouluikäiset lapset ovat hoidostaan sairaalassa Suomessa. Sinun mielipiteesi on tärkeä asian selvittämiseksi.

- Vastaa joka kohtaan.
- Vastaa kysymyksiin rehellisesti, ihan niin kuin itse ajattelet.
- Sinun ei tarvitse kirjoittaa nimeäsi vihkoon.
- Kun olet vastannut vihkoon, laita se kirjekuoreen ✉ ja sulje se.
- Anna kirjekuori hoitajille ennen kuin lähdet sairaalasta kotiin. He palauttavat sen minulle.
- Hoitajat antavat sinulle pienen lahjan, kun olet vastannut.
- Kukaan ei saa tietää, mikä on juuri Sinun täyttämäsi vihko.

Vastauksiasi käytän tutkimuksessani, jota teen Turun yliopiston hoitotieteen laitoksella.

Vastaaminen on vapaaehtoista, mutta toivon Sinun vastaavan, koska pidän Sinun mielipidettäsi tärkeänä.

Kiitos Sinulle!

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Vastaa kysymyksiin laittamalla rasti (X) sopivaan vaihtoehtoon tai kirjoita vastaus viivalle.

1. *Olen*
    a) tyttö
    b) poika

2. *Olen* __________ vuotta vanha

3. Tulin sairaalaan,
    a) koska siitä oli etukäteen sovittu
    b) koska loukkasin itseni
    c) koska tulin äkkiä kipeäksi

4. *Olen* nyt sairaalassa, koska minulla on ____.

5. *Olen* nyt ollut sairaalassa
    a) 1 yön
    b) 2 yötä
    c) 3 yötä
    d) 4 yötä
    e) 5 yötä tai enemmän

jatkuu

6. Sairaalassa,
    a) olen ollut huoneessa, jossa vain minä olen ollut potilaana
    b) olen ollut huoneessa, jossa on ollut myös muita potilaana olevia lapsia
    c) olen ollut huoneessa, jossa olen ollut yksin sekä huoneessa, jossa on ollut myös muita potilaana olevia lapsia

7. Olen aikaisemmin ollut sairaalassa yötä
    a) kyllä
    b) en
    c) en tiedä
    d) en muista

8. Vanhempani ovat olleet tällä kertaa kanssani sairaalassa
    a) koko ajan
    b) päivällä, mutta ei yöllä
    c) kun tulin sairaalaan ja kun pääsen kotiin

9. Minulla on ollut sairaalassa oma hoitaja
    a) kyllä, hoitajani nimi on____
    b) ei
    c) en tiedä

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Millaiset hoitajat Sinua ovat sairaalassa hoitaneet?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina olleet tällaisia.
Rastita 😐 naama, jos hoitajat mielestäsi ovat joskus olleet tällaisia.
Rastita ☹ naama, jos hoitajat mielestäsi eivät koskaan ole olleet tällaisia.

Hoitajani ovat olleet	AINA	JOSKUS	EI KOSKAAN
10. kilttejä	☺	😐	☹
11. taitavia	☺	😐	☹
12. ilkeitä	☺	😐	☹
13. kiireisiä	☺	😐	☹
14. kivoja	☺	😐	☹
15. ikäviä	☺	😐	☹
16. hauskoja	☺	😐	☹
17. pitkästyttäviä	☺	😐	☹
18. rehellisiä	☺	😐	☹

Hoitajillani on ollut	AINA	JOSKUS	EI KOSKAAN
19. valkoiset vaatteet	☺	😐	☹
20. värikkäät vaatteet	☺	😐	☹

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Mitä hoitajat ovat tehneet Sinun kanssasi?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina tehneet kanssasi näin.

Rastita 😐 naama, jos hoitajat ovat joskus tehneet kanssasi näin.

Rastita ☹ naama, jos hoitajat eivät koskaan ole tehneet kanssasi näin.

Hoitajat ovat	AINA	JOSKUS	EI KOSKAAN
21. leikkineet ja/tai pelanneet kanssani	☺	😐	☹
22. jutelleet kanssani minua kiinnostavista asioista	☺	😐	☹
23. pitäneet hyvää huolta minusta	☺	😐	☹
24. hoitaneet minua niin, että muut lapset tai vanhemmat ovat nähneet minut ilman vaatteita	☺	😐	☹
25. kuunnelleet minua	☺	😐	☹
26. ottaneet mielipiteeni huomioon	☺	😐	☹
27. rohkaisseet minua	☺	😐	☹
28. lohduttaneet minua	☺	😐	☹
29. kertoneet, mitä voin ja saan itse tehdä sairaalassa	☺	😐	☹
30. antaneet minun itse osallistua omaan hoitooni	☺	😐	☹
31. hoitaneet minua yhdessä vanhempien kanssa	☺	😐	☹
32. selittäneet asiat niin, että olen ne ymmärtänyt	☺	😐	☹
33. kannustaneet minua kysymään	☺	😐	☹
34. huomioineet, mistä ruuista pidän	☺	😐	☹

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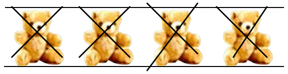
Laita rasti ruutuun, jos ET OLE tarvinnut hoitajien apua seuraavissa asioissa	AINA	JOSKUS	EI KOSKAAN
35. hoitaneet kipujani minulla ei ole ollut kipuja ☐	☺	😐	☹
36. auttaneet minua syömisessä en ole tarvinnut apua ☐	☺	😐	☹
37. auttaneet minua pesuissa en ole tarvinnut apua ☐	☺	😐	☹
38. auttaneet minua vessassa käynneissä en ole tarvinnut apua ☐	☺	😐	☹

Mitä asioita ja kuinka paljon hoitajat ovat Sinulle kertoneet?

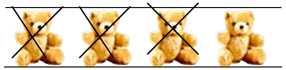
Hoitajat ovat mielestäni kertoneet minulle	TARPEEKSI	JONKUN VERRAN	EI LAINKAAN
39. miksi olen sairaalassa	☺	😐	☹
40. miten sairauttani hoidetaan	☺	😐	☹
41. mitä sairaalassa päivän aikana tapahtuu	☺	😐	☹
42. lääkkeistäni	☺	😐	☹
43. toimenpiteistäni (kuten verinäytteen tai röntgenkuvan ottamisesta)	☺	😐	☹
44. mitä voin syödä ja juoda	☺	😐	☹
45. missä ja miten voin liikkua sairaalassa	☺	😐	☹
46. kauanko joudun olemaan sairaalassa	☺	😐	☹
47. miten hoidan itseäni, kun pääsen sairaalasta kotiin	☺	😐	☹
48. milloin voin mennä kouluun	☺	😐	☹
49. milloin voin osallistua harrastuksiini	☺	😐	☹

jatkuu

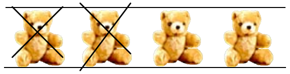
Mitä mieltä olet seuraavista asioista?



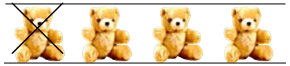
Rastita 4 nallea, jos olet asiasta täysin samaa mieltä.



Rastita 3 nallea, jos olet asiasta jonkin verran samaa mieltä.



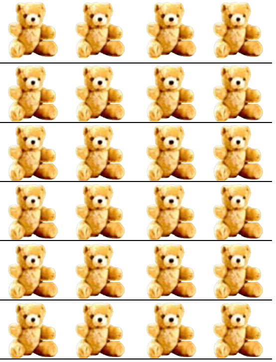
Rastita 2 nallea, olet asiasta jonkin verran eri mieltä.



Rastita 1 nalle, jos olet asiasta täysin eri mieltä.
Vastaa joka kohtaan!

Sairaalassa

50. aikani on kulunut hyvin esimerkiksi pelaamalla, katselemalla videoita, lukemalla ja leikkimällä
51. on ollut tarpeeksi kirjoja ja lehtiä
52. on ollut tarpeeksi videoita ja pelejä
53. on ollut tarpeeksi askartelua
54. on ollut tarpeeksi leluja
55. on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa



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56. on ollut kodikasta ja viihtyisää	🧸	🧸	🧸	🧸
57. on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen	🧸	🧸	🧸	🧸
58. olen voinut olla yksin omassa rauhassa, jos olen halunnut	🧸	🧸	🧸	🧸
59. vanhemmistani on ollut minulle seuraa	🧸	🧸	🧸	🧸
60. sukulaiseni ovat voineet olla tarpeeksi kanssani	🧸	🧸	🧸	🧸
61. kaverini ovat voineet olla tarpeeksi kanssani	🧸	🧸	🧸	🧸
62. hoitajat ovat olleet tarpeeksi kanssani	🧸	🧸	🧸	🧸
63. olen saanut muista potilaina olevista lapsista kavereita itselleni	🧸	🧸	🧸	🧸
64. olen pelännyt yksinoloa	🧸	🧸	🧸	🧸
65. olen pelännyt pistämistä ja piikkejä	🧸	🧸	🧸	🧸
66. olen pelännyt hoitajia	🧸	🧸	🧸	🧸
67. olen pelännyt lääkäreitä	🧸	🧸	🧸	🧸
68. olen pelännyt kipua	🧸	🧸	🧸	🧸

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69. Minun mielestä kivointa sairaalassa on ollut

70. Minun mielestä ikävintä sairaalassa on ollut

71. Koulussa annetaan numeroita 4-10. Minkä numeron antaisit tällä kertaa hoidollesi sairaalassa? ____________________

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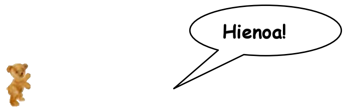
72. Piirrä sairaalan huone, jossa toivoisit, että Sinua hoidettaisiin.
Keitä ihmisiä, mitä tavaroita tai minkä näköistä siellä olisi?
Voit kirjoittaa kuvan alle tai taakse, mitä olet piirtänyt tai pyytää vanhempiasi kirjoittamaan.



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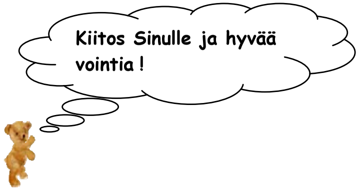
Hienoa, että olet jaksanut vastata kaikkiin kysymyksiin. Kerro vielä, mitä mieltä olit vastaamisesta.

73. Oliko kysymyksiä
    a) liian paljon
    b) sopivasti
    c) liian vähän

74. Miten hyvin jaksoit mielestäsi vastata kysymyksiin?
    a) hyvin
    b) melko hyvin
    c) huonosti

75. Auttoiko joku Sinua vastaamisessa?
    a) Ei
    b) Kyllä, auttoi siten, että
        a) luki kysymykset minulle
        b) kirjoitti vastaukseni
        c) selitti minulle kysymyksiä, jos en niitä ymmärtänyt
    c) muulla tavoin, miten?____



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Hei!

Olen kiinnostunut siitä, mitä mieltä kouluikäiset lapset ovat hoidostaan sairaalassa Suomessa. Sinun mielipiteesi on tärkeä asian selvittämiseksi.

- Vastaa joka kohtaan.
- Vastaa kysymyksiin rehellisesti, ihan niin kuin itse ajattelet.
- Sinun ei tarvitse kirjoittaa nimeäsi vihkoon.
- Kun olet vastannut vihkoon, laita se kirjekuoreen ✉ ja sulje se.
- Anna kirjekuori hoitajille ennen kuin lähdet sairaalasta kotiin. He palauttavat sen minulle.
- Kukaan ei saa tietää, mikä on juuri Sinun täyttämäsi vihko.

Vastauksiasi käytän tutkimuksessani, jota teen Turun yliopiston hoitotieteen laitoksella.

Vastaaminen on vapaaehtoista, mutta toivon Sinun vastaavan, koska pidän Sinun mielipidettäsi tärkeänä.

Kiitos Sinulle!

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Vastaa kysymyksiin laittamalla rasti (X) sopivaan vaihtoehtoon tai kirjoita vastaus viivalle.

1. Olen
    a) tyttö
    b) poika

2. Olen ___________ vuotta vanha

3. Tulin sairaalaan,
    a) koska siitä oli etukäteen sovittu
    b) koska loukkasin itseni
    c) koska tulin äkkiä kipeäksi

4. Olen nyt sairaalassa, koska minulla on ____.

5. Olen nyt ollut sairaalassa
    a) 1 yön
    b) 2 yötä
    c) 3 yötä
    d) 4 yötä
    e) 5 yötä tai enemmän

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6. Sairaalassa,
    a) olen ollut huoneessa, jossa vain minä olen ollut potilaana
    b) olen ollut huoneessa, jossa on ollut myös muita potilaana olevia lapsia
    c) olen ollut huoneessa, jossa olen ollut yksin sekä huoneessa, jossa on ollut myös muita potilaana olevia lapsia

7. Olen aikaisemmin ollut sairaalassa yötä
    a) kyllä
    b) en
    c) en tiedä
    d) en muista

8. Vanhempani ovat olleet tällä kertaa kanssani sairaalassa
    a) koko ajan
    b) päivällä, mutta ei yöllä
    c) kun tulin sairaalaan ja kun pääsen kotiin

9. Minulla on ollut sairaalassa oma hoitaja
    a) kyllä, hoitajani etunimi on____
    b) ei
    c) en tiedä

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Millaiset hoitajat Sinua ovat sairaalassa hoitaneet?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina olleet tällaisia.
Rastita 😐 naama, jos hoitajat mielestäsi ovat joskus olleet tällaisia.
Rastita ☹ naama, jos hoitajat mielestäsi eivät koskaan ole olleet tällaisia.

Hoitajani ovat olleet	AINA	JOSKUS	EI KOSKAAN
10. kilttejä	☺	😐	☹
11. taitavia	☺	😐	☹
12. ilkeitä	☺	😐	☹
13. kiireisiä	☺	😐	☹
14. kivoja	☺	😐	☹
15. ikäviä	☺	😐	☹
16. hauskoja	☺	😐	☹
17. pitkästyttäviä	☺	😐	☹
18. rehellisiä	☺	😐	☹

Hoitajillani on ollut	AINA	JOSKUS	EI KOSKAAN
19. valkoiset vaatteet	☺	😐	☹
20. värikkäät vaatteet	☺	😐	☹

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Mitä hoitajat ovat tehneet Sinun kanssasi?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina tehneet kanssasi näin.

Rastita 😐 naama, jos hoitajat ovat joskus tehneet kanssasi näin.

Rastita ☹ naama, jos hoitajat eivät koskaan ole tehneet kanssasi näin.

Hoitajat ovat	AINA	JOSKUS	EI KOSKAAN
21. leikkineet ja/tai pelanneet kanssani	☺	😐	☹
22. jutelleet kanssani minua kiinnostavista asioista	☺	😐	☹
23. pitäneet hyvää huolta minusta	☺	😐	☹
24. ymmärtäneet, että en halua olla ilman vaatteita muiden lasten ja vanhempien nähden	☺	😐	☹
25. kuunnelleet minua	☺	😐	☹
26. ottaneet mielipiteeni huomioon	☺	😐	☹
27. rohkaisseet minua	☺	😐	☹
28. lohduttaneet minua	☺	😐	☹
29. kertoneet, mitä voin ja saan itse tehdä sairaalassa	☺	😐	☹
30. antaneet minun itse osallistua omaan hoitooni	☺	😐	☹
31. hoitaneet minua yhdessä vanhempien kanssa	☺	😐	☹
32. selittäneet asiat niin, että olen ne ymmärtänyt	☺	😐	☹
33. kannustaneet minua kysymään	☺	😐	☹
34. huomioineet, mistä ruuista pidän	☺	😐	☹

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Laita rasti ruutuun, jos **ET OLE** tarvinnut hoitajien apua seuraavissa asioissa	AINA	JOSKUS	EI KOSKAAN
35. hoitaneet kipujani minulla ei ole ollut kipuja ☐	☺	😐	☹
36. auttaneet minua syömisessä en ole tarvinnut apua ☐	☺	😐	☹
37. auttaneet minua pesuissa en ole tarvinnut apua ☐	☺	😐	☹
38. auttaneet minua vessassa käynneissä en ole tarvinnut apua ☐	☺	😐	☹

Mitä asioita ja kuinka paljon hoitajat ovat Sinulle kertoneet?

Hoitajat ovat mielestäni kertoneet minulle	TARPEEKSI	JONKUN VERRAN	EI LAINKAAN TARPEEKSI
39. miksi olen sairaalassa	☺	😐	☹
40. miten sairauttani hoidetaan	☺	😐	☹
41. lääkkeistäni	☺	😐	☹
42. toimenpiteistäni (kuten verikokeen tai röntgenkuvan ottamisesta)	☺	😐	☹
43. mitä voin syödä ja juoda	☺	😐	☹
44. missä ja miten voin liikkua sairaalassa	☺	😐	☹
45. kauanko joudun olemaan sairaalassa	☺	😐	☹
46. miten hoidan itseäni, kun pääsen sairaalasta kotiin	☺	😐	☹
47. milloin voin mennä kouluun	☺	😐	☹
48. milloin voin osallistua harrastuksiini	☺	😐	☹

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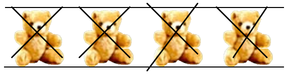
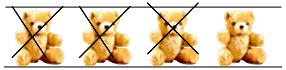
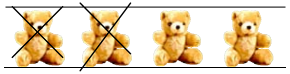
Mitä mieltä olet seuraavista asioista?



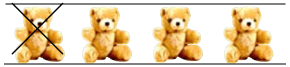
Rastita 4 nallea, jos olet asiasta täysin samaa mieltä.



Rastita 3 nallea, jos olet asiasta jonkin verran samaa mieltä.

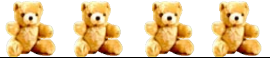
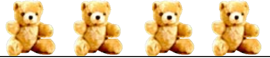
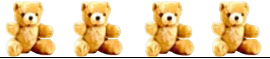
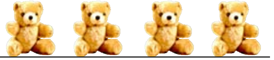
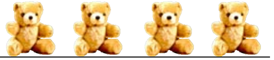


Rastita 2 nallea, olet asiasta jonkin verran eri mieltä.



Rastita 1 nalle, jos olet asiasta täysin eri mieltä.
Vastaa joka kohtaan!

Sairaalassa

49. aikani on kulunut hyvin esimerkiksi pelaamalla, katselemalla videoita, lukemalla ja leikkimällä	
50. on ollut tarpeeksi kirjoja ja lehtiä	
51. on ollut tarpeeksi videoita ja pelejä	
52. on ollut tarpeeksi askartelua	
53. on ollut tarpeeksi leluja	
54. on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa	

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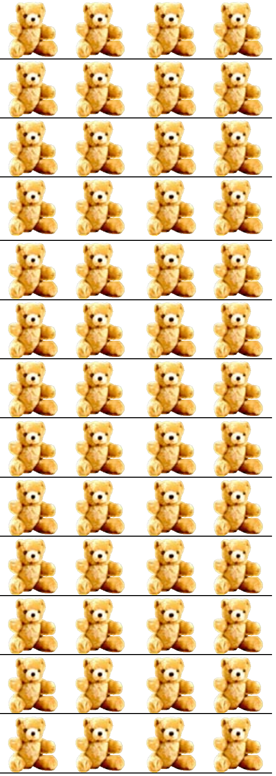
55. on ollut kodikasta ja viihtyisää
56. on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen
57. olen voinut olla yksin omassa rauhassa, jos olen halunnut
58. vanhemmistani on ollut minulle seuraa
59. sukulaiseni ovat voineet olla tarpeeksi kanssani
60. kaverini ovat voineet olla tarpeeksi kanssani
61. hoitajat ovat olleet tarpeeksi kanssani
62. muista potilaina olevista lapsista on ollut minulle seuraa
63. olen pelännyt yksinoloa
64. olen pelännyt pistämistä ja piikkejä
65. olen pelännyt hoitajia
66. olen pelännyt lääkäreitä
67. olen pelännyt kipua



jatkuu

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68. Minun mielestä kivointa sairaalassa on ollut

____

____

____

69. Minun mielestä ikävintä sairaalassa on ollut

____

____

____

70. Koulussa annetaan numeroita 4-10. Minkä numeron antaisit tällä kertaa hoidollesi sairaalassa? ______________

71. Auttoiko joku Sinua vastaamisessa?
   a) Ei
   b) Kyllä, auttoi siten, että
      a) luki kysymykset minulle
      b) kirjoitti vastaukseni
      c) selitti minulle kysymyksiä, jos en niitä ymmärtänyt
      d) muulla tavoin, miten?______________________

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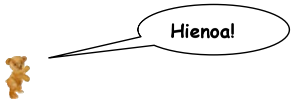
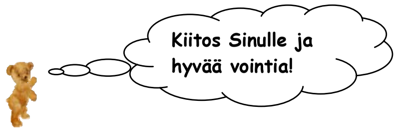
72. Piirrä sairaalan huone, jossa toivoisit, että Sinua hoidettaisiin.
Keitä ihmisiä, mitä tavaroita tai minkä näköistä siellä olisi?
Voit kirjoittaa kuvan alle tai taakse, mitä olet piirtänyt tai pyytää vanhempiasi kirjoittamaan.





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LASTEN OSASTOJEN HOITOHENKILÖKUNTA
- ASIANTUNTEMUSTANNE TARVITAAN LASTEN HOITOTYÖN KEHITTÄMISEKSI

Teen Turun yliopiston hoitotieteen laitoksella väitöskirjaa lasten hoitotyön laadusta. Työni tarkoituksena on selvittää lasten omia kokemuksia sairaalahoitonsa laadusta. Lasten kokemusten selvittämiseksi olen kehittänyt mittarin erityisesti kouluikäisille 7 – 11 -vuotiaille lapsille, jotka ovat sairaalassa vuodeosastohoidossa. Mittarin nimi on ”Minun hoitoni sairaalassa oli” –vihko. Mittari on siis tarkoitettu ja kehitetty nimenomaan lapsille. Mittari on kehitetty lasten hyvän hoidon odotusten pohjalta, jotka on saatu laadullisilla menetelmillä sekä aikaisemman kirjallisuuden perusteella. Tavoitteena on kehittää lapsille oma laadun arviointimittari, jota voitaisiin jatkossa käyttää kokonaan tai osia siitä käytännön lasten hoitotyön laadun arvioinnissa.

Mittarilla kerätään aineistoa Suomen yliopistosairaaloiden lastenosastojen kouluikäisiltä 7 – 11 -vuotiailta lapsilta, jotka ovat ainakin yhden yön sairaalassa. Tämä osasto on yksi niistä. Mittarin arvioinnissa ja kehittämisessä tarvitsen nyt Sinun asiantuntemustasi. Toivon, että suhtaudut tutkimukseen myönteisesti ja vastaat oheiseen kyselylomakkeeseen arvioimalla mittarin soveltuvuutta lasten hoitotyön laadun arviointiin sekä sen soveltuvuutta juuri kouluikäisille lapsille. Ohessa on yksityiskohtaiset vastausohjeet. Lue ne huolellisesti ennen lomakkeen täyttämistä. **Palauta lomake 11.2.2005 mennessä** oheisessa suljetussa kirjekuoressa osastonhoitajallenne, joka lähettää osastonne vastaukset suoraan minulle. Vastauksesi ovat luottamuksellisia eikä henkilöllisyytesi tule missään vaiheessa ilmi.

Tutkimuksen tekemiseen olen saanut sairaalalta asianmukaiset luvat. Tutkimuksen ohjaajana toimii professori Helena Leino-Kilpi Turun yliopiston hoitotieteen laitokselta (02 3338404). Annan mielelläni lisätietoja tutkimukseen liittyvistä asioista.

Yhteistyöterveisin,

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ARVIOINTIOHJEET

Arvioitavana on lasten hoitotyön laatumittari ”Minun hoitoni sairaalassa oli” -vihko. Mittarissa on kolme luokkaa (hoitohenkilökunnan ominaisuudet, hoitotyön toiminnot, hoitotyön ympäristö), jotka sisältävät yhteensä 16 osiota. Kustakin osiosta on lisäksi esitetty osioon kuuluvat mittarin väittämät. Kyselylomake on modifioitu Perälän (1995) lomakkeesta.

Tässä kyselyssä lasten laatumittaria arvioidaan luokittain ja osioittain.

Luokka	Luokan nimi on kirjoitettu isoilla kirjaimilla ja tummennettu taulukon vasemmassa yläreunassa. Esimerkiksi luokka I **HOITOHENKILÖKUNNAN OMINAISUUDET**
Osio	Osiot ovat lomakkeen vasemmassa reunassa numeroituna 1 – 16 kirjoitettuna isoilla ja tummennetuilla kirjaimilla. Esimerkiksi osio 1 **INHIMILLISYYS**
Väittämä	Väittämät ovat lomakkeen vasemmassa reunassa numeroidun osion alla sisennettyinä ja pienillä kirjaimilla kirjoitettuna. Väittämät ovat suoraan kyselylomakkeesta. Kukin osio sisältää 1-10 sen sisältöä kuvaavaa väittämää. Esimerkiksi osion 1 ensimmäinen väittämä Hoitajani ovat olleet kilttejä.

I OSIOKOHTAINEN ARVIOINTI

Tarkastele kutakin osiota erikseen. Osion alla on osion sisältöä kuvaavat väittämät.
Kuhunkin osioon liittyen lomakkeessa on kuusi kysymystä. Kysymykset ja niiden vastausohjeet on esitetty seuraavassa yksityiskohtaisesti. Kyselylomakkeen yläreunassa on vain kysymyksen muistamista helpottavia avainsanoja. Vastauksesi voit kirjoittaa kysymysten alle tai lomakkeen taakse numeroituna.

1. Miten tärkeä osio on hoitotyön laadussa?
    - Arvioi, miten tärkeä osion sisältämä asia on lapsen kannalta hoidon laadussa. Vastaa ympyröimällä mielipidettäsi kuvaava vaihtoehto: Osion sisältämä asia on 1) ei tärkeä, 2) vähän tärkeä, 3) tärkeä, 4) erittäin tärkeä.
    - Halutessasi voit perustella mielipiteesi.

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2. Mittaako osio hoitotyön laatua?
    - Arvioi, mittaako osio yleensä lasten hoitotyön laatua. Vastaa ympyröimällä joko 1) kyllä tai 2) ei
    - Jos osio ei mielestäsi mittaa hoitotyön laatua 2), perustele mielipiteesi.

3. Kuuluuko osio tähän luokkaan?
    - Arvioi, kuuluko osio mielestäsi tarkasteltavaan luokkaan. Vastaa ympyröimällä joko 1) kyllä tai 2) ei.
    - Jos osio ei mielestäsi kuulu arvioitavaan luokkaan 2) perustele mielipiteesi.

4. Mittaako joku muu osio samaa laatutekijää?
    - Tarkastele, mittaako saman tai jonkun toisen luokan osio samaa asiaa. Vastaa ympyröimällä joko 1) kyllä tai 2) ei.
    - Jos joku muu osio mittaa samaa 2), perustele mielipiteesi.

5. Onko osio selkeä?
    - Arvioi osion selkeyttä tarkastelemalla sen yksiselitteisyyttä ja ymmärrettävyyttä.
    - Vastaa ympyröimällä mielipidettäsi kuvaava vaihtoehto: Osion sisältämä asia 1) ei ole selkeä, 2) vähän selkeä, 3) selkeä tai 4) erittäin selkeä.
    - Jos osio ei ole selkeä, perustele mielipiteesi.

6. Onko osio konkreettinen?
    - Arvioi osion konkreettisuutta tarkastelemalla ilmaiseeko osio mittaamansa hoitotyön alueen niin konkreettisesti, että se on mitattavissa. Vastaa ympyröimällä mielipidettäsi kuvaava vaihtoehto: Osion sisältämä asia on 1) ei konkreettinen 2) vähän konkreettinen, 3) konkreettinen 4) erittäin konkreettinen.
    - Jos osio ei ole konkreettinen, perustele mielipiteesi.

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II LUOKITTAINEN ARVIOINTI

Yksittäisten osioiden lisäksi arvioidaan koko luokkaa. Mittarin luokat ovat hoitohenkilökunnan ominaisuudet, hoitotyön toiminnot ja hoitotyön ympäristö. Tarkastele yhtä luokkaa kerrallaan. Tutustu luokan nimeen ja sen sisällön määrittelyyn (osiot ja väittämät).

7. Mittaako luokka hoitotyön laatua?
    - Arvioi, onko kyseisen luokan osoittama asia keskeinen lasten hoitotyön laadulle. Vastaa ympyröimällä 1) kyllä tai 2) ei.
    - Jos luokka ei mittaa hoitotyön laatua 2), perustele mielipiteesi.

8. Miten hyvin, tämän luokan osiot kattavat luokan tarkoittaman hoitotyön alueen?
    - Tarkastele, miten hyvin luokan osiot kattavat luokan nimen osoittaman sisällön. Vastaa ympyröimällä mielipidettäsi kuvaava vaihtoehto:1) ei ollenkaan, 2) huonosti, 3) tyydyttävästi tai 4) hyvin.
    - Jos luokan osiot eivät kata luokan tarkoittamaa hoitotyön aluetta, perustele mielipiteesi.

9. Mitkä alueet puuttuvat luokasta?
    - Lisää asioita, jotka luokasta mielestäsi puuttuu.

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Vastaa ympyröimällä ja perustele tarvittaessa vastauksesi kysymyksen alle tai paperin kääntöpuolelle. Yksityiskohtaiset vastusohjeet löydät erillisestä ohjeesta.

1. Sairaala, jossa työskentelet ____

2. Osasto, jolla työskentelet ____

3. Peruskoulutuksesi
    1) sairaanhoitaja/erikoissairaanhoitaja
    2) lastenhoitaja/perushoitaja/lähihoitaja
    3) muu, mikä ____

4. Työkokemuksesi lasten hoitotyöstä __________vuotta ja __________________________kuukautta.

5. Onko osastollanne kokemusta hoitotyön laadun kehittämisestä?
    1) Ei
    2) Kyllä, minkälaista ____
    ____

6. Onko osastollanne kokemusta hoitotyön laadun kehittämisestä lasten näkökulmasta?
    1) Ei
    2) Kyllä, minkälaista ____
    ____

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LUOKKA I HOITOHENKILÖKUNNAN OMINAISUUDET OSIOT (1- 5) ja väittämät (10- 20)	**1.MITEN TÄRKEÄ?** **1. ei tärkeä** **2. vähän tärkeä** **3. tärkeä** **4. erittäin tärkeä**	**2.MITTAAKO OSIO LAATUA?** **1. kyllä** **2. ei**	**3.KUULUUKO OSIO TÄHÄN LUOKKAAN?** **1. kyllä** **2. ei**	**4. MITTAAKO JOKU MUU OSIO SAMAA?** **1. kyllä** **2. ei**	**5. SELKEYS** **1 ei ole selkeä** **2 vähän selkeä** **3 selkeä** **4 erittäin selkeä**	**6.KONKREETTISUUS** **1 ei konkreetti** **2 vähän konkreetti** **3 konkreetti** **4 erittäin konkreetti**
1.INHIMILLISYYS Hoitajani ovat olleet 10. kilttejä 12. ilkeitä 13. kiireisiä 14. kivoja 15. ikäviä	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
2. AMMATTITAITO Hoitajani ovat olleet 11. taitavia	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
3. HUUMORINTAJUISUUS Hoitajani ovat olleet 16. hauskoja 17. pitkästyttäviä	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
4. LUOTETTAVUUS Hoitajani ovat olleet 18. rehellisiä	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
5. ULKOINEN OLEMUS Hoitajillani on ollut 19. valkoiset vaatteet 20. värikkäät vaatteet	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

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7. Mittaako luokka ”hoitohenkilökunnan ominaisuudet” laatua?

1) Kyllä
2) Ei, perustelu ______________________________

____

____

8. Miten hyvin tämän luokan ” hoitohenkilökunnan ominaisuudet” osiot kattavat luokan tarkoittaman hoitotyön alueen?

1) Hyvin
2) Tyydyttävästi
3) Huonosti
4) Ei ollenkaan, perustelu ______________________________

____

9. Mitkä keskeiset alueet puuttuvat luokasta ” hoitohenkilökunnan ominaisuudet”?______________________________

____

____

____

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LUOKKA II **HOITOTYÖN TOIMINNOT** **OSIOT (6 - 13)** **ja väittämät (21- 48)**	**1.MITEN TÄRKEÄ?** **1. ei tärkeä** **2. vähän tärkeä** **3. tärkeä** **4. erittäin tärkeä**	**2.MITTAAKO OSIO LAATUA?** **1. kyllä** **2. ei**	**3. KUULUUKO OSIO TÄHÄN LUOKKAAN?** **1. kyllä** **2. ei**	**4. MITTAAKO JOKU MUU OSIO SAMAA?** **1. kyllä** **2. ei**	**5. SELKEYS** **1 ei ole selkeä** **2 vähän selkeä** **3 selkeä** **4 erittäin selkeä**	**6. KONKREETTISUUS** **1 ei konkreetti** **2 vähän konkreetti** **3 konkreetti** **4 erittäin konkreetti**
6. VIIHDYTTÄMINEN Hoitajat ovat 21. leikkineet ja/tai pelanneet kanssani 22. jutelleet kanssani minua kiinnostavista asioista	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
7. AUTTAMINEN JA HUOLENPITO Hoitajat ovat 23. pitäneet hyvää huolta minusta 24. ymmärtäneet, että en halua olla ilman vaatteita muiden lasten ja vanhempien nähden	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
8. KUNNIOITTAMINEN JA VUOROVAIKUTUS Hoitajat ovat 25. kuunnelleet minua 26. ottaneet mielipiteeni huomioon	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
9. TURVALLISUUDEN TUOMINEN Hoitajat ovat 27. rohkaisseet minua 28. lohduttaneet minua	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
10. OMATOIMISUUDEN TUKEMINEN Hoitajat ovat 29. kertoneet, mitä voin ja saan itse tehdä sairaalassa 30. antaneet minun itse osallistua omaan hoitooni 31. hoitaneet minua yhdessä vanhempien kanssa	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

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LUOKKA II HOITOTYÖN TOIMINNOT jatkuu	**1.MITEN TÄRKEÄ? 1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä**	**2.MITTAAKO OSIO LAATUA? 1. kyllä 2. ei**	**3. KUULUUKO OSIO TÄHÄN LUOKKAAN? 1. kyllä 2. ei**	**4. MITTAAKO JOKU MUU OSIO SAMAA? 1. kyllä 2. ei**	**5. SELKEYS 1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä**	**6. KONKREETTISUUS 1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti**
11. FYYSINEN HOITAMINEN Hoitajat ovat 34. huomioineet, mistä ruuista pidän 35. hoitaneet kipujani 36. auttaneet minua syömisessä 37. auttaneet minua pesuissa 38. auttaneet minua vessassa käynneissä	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
12. OHJAAMINEN JA TIEDON ANTAMINEN Hoitajat ovat 32. selittäneet asiat niin, että olen ne ymmärtänyt 33. kannustaneet minua kysymään	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
13. TIEDON ALUEET Hoitajat ovat mielestäni kertoneet minulle 39. miksi olen sairaalassa 40. miten sairauttani hoidetaan 41. lääkkeistäni 42. toimenpiteistäni (kuten verikokeen tai röntgenkuvan ottamisesta) 43. mitä voin syödä ja juoda 44. missä ja miten voin liikkua sairaalassa 45. kauanko joudun olemaan sairaalassa 46. miten hoidan itseäni, kun pääsen sairaalasta kotiin 47. milloin voin mennä kouluun 48. milloin voin osallistua harrastuksiini	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

Turun Yliopisto
Tiina Pelander, modifioitu Perälä (1995)

Appendix 13

12/2004 10/12

10. Mittaako luokka ”hoitotyön toiminnot” laatua?
    1) Kyllä
    2) Ei, perustelu ____

____

____

11. Miten hyvin tämän luokan ” hoitotyön toiminnot” osiot kattavat luokan tarkoittaman hoitotyön alueen?
    1) Hyvin
    2) Tyydyttävästi
    3) Huonosti
    4) Ei ollenkaan, perustelu ____

____

____

____

12. Mitkä keskeiset alueet puuttuvat luokasta ” hoitotyön toiminnot”?______________________________

____

____

____

Appendix 13

LUOKKA III **HOITOTYÖN YMPÄRISTÖ** **OSIOT (14- 16)** **ja väittämät (49-67)**	**1.MITEN TÄRKEÄ?** **1. ei tärkeä** **2. vähän tärkeä** **3. tärkeä** **4. erittäin tärkeä**	**2. MITTAAKO OSIO LAATUA?** **1. kyllä** **2. ei**	**3. KUULUUKO OSIO TÄHÄN LUOKKAAN?** **1. kyllä** **2. ei**	**4. MITTAAKO JOKU MUU OSIO SAMAA?** **1. kyllä** **2. ei**	**5. SELKEYS** **1 ei ole selkeä** **2 vähän selkeä** **3 selkeä** **4 erittäin selkeä**	**6. KONKREETTISUUS** **1 ei konkreetti** **2 vähän konkreetti** **3 konkreetti** **4 erittäin konkreetti**
14. FYYSINEN YMPÄRISTÖ Sairaalassa 49. aikani on kulunut hyvin esimerkiksi pelaamalla, katselemalla videoita, lukemalla ja leikkimällä 50. on ollut tarpeeksi kirjoja ja lehtiä 51. on ollut tarpeeksi videoita ja pelejä 52. on ollut tarpeeksi askartelua 53. on ollut tarpeeksi leluja 54. on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa 55. on ollut kodikasta ja viihtyisää 56. on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
15. SOSIAALINEN YMPÄRISTÖ 57. olen voinut olla yksin omassa rauhassa, jos olen halunnut 58. vanhemmistani on ollut minulle seuraa 59.sukulaiseni ovat voineet olla tarpeeksi kanssani 60. kaverini ovat voineet olla tarpeeksi kanssani 61. hoitajat ovat olleet tarpeeksi kanssani 62. muista potilaina olevista lapsista on ollut minulle seuraa	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti
16. PSYYKKINEN YMPÄRISTÖ 63. olen pelännyt yksinoloa 64. olen pelännyt pistämistä ja piikkejä 65. olen pelännyt hoitajia 66. olen pelännyt lääkäreitä 67. olen pelännyt kipua	1. ei tärkeä 2. vähän tärkeä 3. tärkeä 4. erittäin tärkeä	1. kyllä 2. ei	1. kyllä 2. ei	1. kyllä 2. ei	1 ei ole selkeä 2 vähän selkeä 3 selkeä 4 erittäin selkeä	1 ei konkreetti 2 vähän konkreetti 3 konkreetti 4 erittäin konkreetti

Turun Yliopisto
Tiina Pelander, modifioitu Perälä (1995)

Appendix 13
12/2004 12/12

13. Mittaako luokka ”hoitotyön ympäristö” laatua?

1) Kyllä
2) Ei, perustelu

14. Miten hyvin tämän luokan ” hoitotyön ympäristö” osiot kattavat luokan tarkoittaman hoitotyön alueen?

1) Hyvin
2) Tyydyttävästi
3) Huonosti
4) Ei ollenkaan, perustelu

15. Mitkä keskeiset alueet puuttuvat luokasta ” hoitotyön ympäristö”?

SUURKIITOKSET TYÖSTÄSI!

1/3

Appendix 14. Development of the content of the “Child Care Quality at Hospital” CCQH Instrument

CCQH0 69 (66 + 2 open + drawing)	**CCQHI 63 (60 + 2 open + drawing)**	**CCQHII 63 (59 +3 open + drawing)**	**CCQHIII 62 (58 + 3 open + drawing)**
CHARACTERISTICS: 12	**CHARACTERISTICS: 12**	**CHARACTERISTICS: 11**	**CHARACTERISTICS: 11**
Humanity 5	**Humanity 6**	**Humanity 5**	**Humanity 5**
Nice	Nice	Nice	Nice
	Dull	Dull	Dull
Angry	Bossy	Mean	Mean
Busy	Busy	Busy	Busy
	Calm		
Helpful			
Polite			
	Kind	Kind	Kind
Competence 1	**Competence 0**	**Competence 1**	**Competence 1**
Good in taking care of children		Skilful	Skilful
Sense of humour 2	**Sense of humour 2**	**Sense of humour 2**	**Sense of humour 2**
Cheerful	Funny	Funny	Funny
Boring	Boring	Boring	Boring
Trustworthiness 2	**Trustworthiness 2**	**Trustworthiness 1**	**Trustworthiness 1**
Honest	Honest	Honest	Honest
Reliable	Not reliable		
Appearance 2	**Appearance 2**	**Appearance 2**	**Appearance 2**
Colourful clothes	Colourful clothes	Colourful clothes	Colourful clothes
White clothes	White clothes	White clothes	White clothes
ACTIVITIES 29	**ACTIVITIES 25**	**ACTIVITIES 29**	**ACTIVITIES 28**
Entertainment 2	**Entertainment 2**	**Entertainment 2**	**Entertainment 2**
Plays with children	Plays with children	Plays with children	Plays with children
Watches TV or/and video with children	Watches TV or/and video with children	Talks about interesting things	Talks about interesting things
Caring and communication 8	**Caring and communication 6**	**Caring and communication 6**	**Caring and communication 6**
Helps	Helps	Helps	Helps
Protects intimacy	Protects intimacy	Protects intimacy	Protects intimacy
Listens	Listens	Listens	Listens
Considers child’s opinions	Considers child’s opinions	Considers child’s opinions	Considers child’s opinions
Understands what children tried to say			
Being with children			
Comforts	Comforts	Comforts	Comforts
Reduces children’s fears	Encourages child	Encourages child	Encourages child

2/3

CCQH 0	CCQH I	CCQH II	CCQH III
Supporting initiative 3	**Supporting initiative 3**	**Supporting initiative 3**	**Supporting initiative 3**
Informs child of what s/he can do	Informs child of what s/he can do	Informs child of what s/he can do	Informs child what s/he can do
Cares for child together with parents	Cares for child together with parents	Cares for child together with parents	Cares for child together with parents
Let my parents stay with be			
	Encourages participation in care	Encourages participation in care	Encourages participation in care
Physical care and treatment 5	**Physical care and treatment 4**	**Physical care and treatment 5**	**Physical care and treatment 5**
Provides relief for pain	Provides relief for pain	Provides relief for pain	Provides relief for pain
Helps with eating	Helps with eating	Helps with eating	Helps with eating
Helps with bathing	Helps with bathing	Helps with bathing	Helps with bathing
Helps with toileting	Helps with toileting	Helps with toileting	Helps with toileting
Observes children’s condition			
		Takes account of child’s food preferences	Takes account of child’s food preferences
Education 11	**Education 10**	**Education 13**	**Education 12**
Information that is easy to understand	Information that is easy to understand	Information that is easy to understand	Information that is easy to understand
		Encourages child to ask questions	Encourages child to as questions
Hospital day	Hospital day	Hospital day	
	Explains beforehand what is going to happen		
Reason for hospitalization	Reason for hospitalization	Reason for hospitalization	Reason for hospitalization
Treatment	Treatment	Treatment	Treatment
Medication	Medication	Medication	Medication
Eating and drinking	Eating and drinking	Eating and drinking	Eating and drinking
Moving in hospital	Moving in hospital	Moving in hospital	Moving in hospital
Procedures	Procedures	Procedures	Procedures
Home care instructions	Home care instructions	Home care instructions	Home care instructions
Going to school		Going to school	Going to school
Leisure activities		Leisure activities	Leisure activities
		Duration of hospitalization	Duration of hospitalization

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CCQH 0	CCQH I	CCQH II	CCQH III
Nursing environment 25	**Nursing environment 23**	**Nursing environment 19**	**Nursing environment 19**
Physical 15	**Physical 12**	**Physical 8**	**Physical 8**
Time passes quickly	Time passes quickly	Time passes quickly	Time passes quickly
Enough books + magazines	Enough books + magazines	Enough books + magazines	Enough books + magazines
Enough videos and TV	Enough videos and TV	Enough videos and games	Enough videos and games
Enough games	Enough games		
Enough crafts	Enough crafts	Enough crafts	Enough crafts
Enough toys	Enough toys	Enough toys	Enough toys
Enough windows			
Enough space for my parents, e.g. to spend the night	Enough space for my parents, e.g. to spend the night		
Place to talk and play with my parents	Place to talk and play with my parents and guests	Place to talk and play with my parents and guests	Place to talk and play with my parents and
Enough other children in the same room			
Cosy and pleasant	Cosy and pleasant	Cosy and pleasant	Cosy and pleasant
Furniture suitable for children	Furniture suitable for children		
Clean	Clean		
Easy to find different places	Easy to find different places	Easy to find different places	Easy to find different places
Good food			
Social 5	**Social 6**	**Social 6**	**Social 6**
Privacy	Privacy	Privacy	Privacy
Parents provide company	Parents provide company	Parents provide company	Parents provide company
Sisters and brothers company	Sisters and brothers company	Relatives can visit	Relatives can visit
Grandparents provide company	Grandparents provide company		
		Friends can visit	Friends can visit
		Nurses provide company	Nurses provide company
Other child patients provide company	Other child patients provide company	Other child patients provide company	Other child patients provide company
	Disturbed by other children		
Emotional 5	**Emotional 5**	**Emotional 5**	**Emotional 5**
Feel safe at hospital	Afraid of hospital		
Afraid of other children	Afraid of other children		
Afraid of machines and equipments	Afraid of machines and equipments		
	Afraid of being alone	Afraid of being alone	Afraid of being alone
	Afraid of injections	Afraid of injections	Afraid of injections
Afraid of nurses and doctors	Afraid of nurses and doctors	Afraid of nurses	Afraid of nurses
		Afraid of doctors	Afraid of doctors
		Afraid of pain	Afraid of pain
Parents help with fears			

Appendix 15
1/4

Tiina Pelander
Turun yliopisto, Hoitotieteen laitos

HYVÄT VANHEMMAT

Teen Turun yliopiston lääketieteellisen tiedekunnan hoitotieteen laitoksella väitöskirjaa lasten hyvästä hoidosta. Työni tarkoituksena on selvittää lasten kokemuksia ja odotuksia hoidostaan eli miltä hoitaminen näyttää lapsen silmin. Tulosten avulla voidaan lapsipotilaiden hoidon laatua kehittää siten, että lapsen oma näkökulma tulee aikaisempaa paremmin huomioiduksi. Tutkimuksen tekemiseen olen saanut sairaalalta asianmukaiset luvat.

Tutkimuksessa keskustellaan lapsenne kanssa hänen sairaalahoidon aikaisista kokemuksistaan ja odotuksistaan. Keskustelu toteutuu lapsenne sairaalassa olon aikana ja sen arvioitu kesto on puoli tuntia. Keskustelu nauhoitetaan teidän ja lapsenne luvalla. Keskustelun lisäksi pyydän lasta piirtämään siitä, millaista sairaalassa tulisi olla. Keskusteluaineisto sekä piirrokset käsitellään luottamuksellisesti, eikä lapsenne henkilöllisyys ole tunnistettavissa tuloksissa. Vanhemmat voivat halutessaan olla läsnä keskustelutilaisuudessa, mutta se ei ole välttämätöntä.

Lapsenne antamat tiedot ovat tutkimuksen kannalta arvokkaita ja tärkeitä, siksi toivonkin, että antaisitte luvan lapsenne kanssa keskusteluun. Jos suostutte, että lapsenne osallistuu tutkimukseen, niin antakaa mukana oleva lomake täytettynä osaston sairaanhoitajalle. Sovin keskusteluajan osaston sairaanhoitajan kanssa. Lapsenne yhteystiedot ja sairauskertomus eivät ole käytettävissäni. Lapselta pyydetään suullinen suostumus keskusteluun vanhempien antaman luvan jälkeen. Tutkimukseen osallistuminen on vapaaehtoista, ja sen voi halutessaan keskeyttää, eikä se vaikuta mitenkään lapsenne hoitoon.

Annan mielelläni lisätietoja tutkimukseen liittyvistä asioista.

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Appendix 15
2/4

Tiina Pelander
Turun yliopisto, Hoitotieteen laitos

LASTEN HOITOTYÖN LAATU JA SEN ARVIOINTI

LAPSEN NIMI:

____

ANNAN LUVAN LAPSENI KESKUSTELUUN OSALLISTUMISELLE:

____

Huoltajan allekirjoitus ja nimenselvennys

____

Päiväys

Appendix 15
3/4

Tiina Pelander
Turun yliopisto, Hoitotieteen laitos

HYVÄT VANHEMMAT

Teen Turun yliopiston lääketieteellisen tiedekunnan hoitotieteen laitoksella väitöskirjaa lasten hyvästä hoidosta. Työni tarkoituksena on selvittää lasten kokemuksia ja odotuksia hoidostaan eli miltä hoitaminen näyttää lapsen silmin. Tulosten avulla voidaan lapsipotilaiden hoidon laatua kehittää siten, että lapsen oma näkökulma tulee aikaisempaa paremmin huomioiduksi. Tutkimuksen tekemiseen olen saanut sairaalalta asianmukaiset luvat.

Tutkimuksessa keskustellaan lapsenne kanssa hänen sairaalahoidon aikaisista kokemuksistaan ja odotuksistaan. Keskustelun arvioitu kesto on puoli tuntia. Se nauhoitetaan teidän ja lapsenne luvalla. Keskustelun lisäksi pyydän lasta piirtämään siitä, millaista sairaalassa tulisi olla. Keskusteluaineisto sekä piirrokset käsitellään luottamuksellisesti, eikä lapsenne henkilöllisyys ole tunnistettavissa tuloksissa. Vanhemmat voivat halutessaan olla läsnä keskustelutilaisuudessa, mutta se ei ole välttämätöntä.

Lapsenne antamat tiedot ovat tutkimuksen kannalta arvokkaita ja tärkeitä, siksi toivonkin, että antaisitte luvan lapsenne kanssa keskusteluun. Jos suostutte, että lapsenne osallistuu tutkimukseen, niin lähettäkää mukana oleva suostumuslomake yhteystietojenne kanssa minulle palautuskuoressa, jonka postimaksu on maksettu. Suostumuslomakkeenne saatuani otan yhteyttä teihin, jotta voimme sopia teille parhaiten sopivan keskustelupaikan ja ajan, esimerkiksi poliklinikkakäyntinne yhteyteen. Lapselta pyydetään suullinen suostumus keskusteluun vanhempien antaman luvan jälkeen. Diabeteshoitaja on lähettänyt tämän kirjeen teille, yhteystietonne ja lapsenne sairauskertomus eivät ole käytettävissäni. Tutkimukseen osallistuminen on vapaaehtoista, ja sen voi halutessaan keskeyttää, eikä se vaikuta mitenkään lapsenne hoitoon.

Annan mielelläni lisätietoja tutkimukseen liittyvistä asioista.
Kiitoksin

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Appendix 15
4/4

Tiina Pelander
Turun yliopisto, Hoitotieteen laitos

LASTEN HOITOTYÖN LAATU JA SEN ARVIOINTI

LAPSEN NIMI:

____

ANNAN LUVAN LAPSENI KESKUSTELUUN OSALLISTUMISELLE:

____
Huoltajan allekirjoitus ja nimenselvennys

____
Osoite ja puhelinnumero

____
Päiväys

Appendix 16

Turun Yliopisto
Hoitotieteen laitos
Tiina Pelander
8.10.2004

TIEDOTE HENKILÖKUNNALLE

LASTEN HOITOTYÖN LAATU - KOULUIKÄISTEN LASTEN NÄKÖKULMASTA

Tämä osasto osallistuu tutkimukseen, jossa kouluikäiset lapset arvioivat toteutuneen hoidon laatua. Seuraavassa ohjeita siihen, ketkä lapset kuuluvat tutkimukseen ja miten tutkimus etenee.

KETKÄ LAPSET OSALLISTUVAT?

- 7 –11 -vuotiaat koululaiset
- Lapsi on ollut sairaalassa ainakin yhden yön
- Suomenkielinen
- Lapsen vointi sellainen, että pystyy vastaamaan
- Lapsen kehitys mahdollistaa vastaamisen yksin tai autettuna
- Hyvissä ajoin ennen kotiinlähtöä

MITEN TUTKIMUS ETENEE?

1. Kirjallinen tieto tutkimuksesta ja suostumuslomake vanhemmalle -> kirjallinen suostumus

(suostumuslomake säilytetään osastolla tutkimuksen valmistumiseen saakka)

2. Lapsen suullinen suostumus
3. ”Minun hoitoni sairaalassa oli” –vihko ja kynät lapselle, lapsi laittaa vastattuaan lomakkeensa suljettuna kirjekuoreeseen
4. Lasten vastaukset kerätään osastolle samaan paikkaan

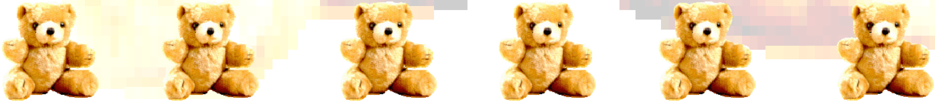
(yhteispostitus tutkijalle tai tutkija hakee kirjekuoret osastolta)

5. Lapsen palkitseminen vastaamisen jälkeen (kynä/tarra)

(tutkija toimittaa palkkiot osastolle)

YHTEYDENPITO

Tutkija on yhteydessä osastolle ainakin kerran viikossa puhelimitse tai käymällä.
Jos tutkimuksesta jotakin kysyttävää soita tai lähetä postia
Tiina Pelander 044 777 6529, e-mail:tiina.pelander@utu.fi
Tutkimuksen ohjaaja: Professori Helena Leino-Kilpi 02 333 8404



TURUN YLIOPISTO
Hoitotieteen laitos
20014 Turku
Tiina Pelander

TIEDOTE/SUOSTUMUSASIAKIRJA **Appendix 17**
1/2

LASTEN HOITOTYÖN LAATU - KOULUIKÄISTEN LASTEN NÄKÖKULMASTA

HYVÄT VANHEMMAT/ VANHEMPI,

Teen Turun yliopiston hoitotieteen laitoksella väitöskirjaa lasten hoitotyön laadusta. Työni tarkoituksena on selvittää lasten omia kokemuksia sairaalahoidostaan. Lasten hoitotyötä on tutkittu vähän sekä Suomessa että ulkomailla lasten näkökulmasta, joten on tärkeää, että lapsenne voi halutessaan osallistua tutkimukseen. Tutkimusaineisto tullaan keräämään kaikista Suomen yliopistosairaaloiden lastenosastoilta, joissa hoidetaan 7- 11 -vuotiaita lapsia, jotka ovat olleet ainakin yhden yön sairaalassa.

Lapsenne antamat tiedot ovat tutkimuksen kannalta arvokkaita ja tärkeitä, siksi toivonkin, että lapsenne voisi osallistua tähän tutkimukseen. Jos Te ja lapsenne suostutte osallistumaan tutkimukseen, niin antakaa ohessa oleva kirjallinen suostumuslomake täytettynä osaston hoitajalle. Lapsenne saa sitten ”Minun hoitoni sairaalassa oli” –vihon vastattavaksi. Vihossa on kysymyksiä lapsenne nyt saamasta hoidosta sekä piirustustehtävä.

Toivon, että lapsenne vastaisi itsenäisesti kysymyksiin ennen kotiin lähtöään, mutta voitte olla tarvittaessa hänen apunaan. Tutkimukseen osallistuminen on vapaaehtoista, ja vastaamisen voi halutessaan keskeyttää, eikä se vaikuta mitenkään lapsenne saamaan hoitoon sairaalassa. Lapsenne vastaukset käsitellään luottamuksellisesti, eikä lapsenne henkilöllisyys tule esiin missään tutkimuksen vaiheessa. Täytetyt lomakkeet palautuvat tutkijalle suljetussa kirjekuoressa. Antamanne tiedot säilytetään osastolla ja hävitetään tutkimuksen valmistuttua vuonna 2006.

Tutkimuksen tekemiseen olen saanut sairaalalta asianmukaiset luvat, ja hoitohenkilökunta on tietoinen tutkimuksesta. Tutkimuksen ohjaajana toimii professori Helena Leino-Kilpi Turun yliopiston hoitotieteen laitokselta (02 3338404). Annan mielelläni lisätietoja tutkimukseen liittyvistä asioista.

Kiitos yhteistyöstänne,

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TURUN YLIOPISTO TIEDOTE/SUOSTUMUSASIAKIRJA **Appendix 17**
Hoitotieteen laitos 2/2
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LASTEN HOITOTYÖN LAATU
- KOULUIKÄISTEN LASTEN NÄKÖKULMASTA

Olen saanut selvityksen tutkimuksen tarkoituksesta ja tulosten käytöstä. **ANNAN SUOSTUMUKSEN SIIHEN, ETTÄ LAPSENI VOI OSALLISTUA LASTEN HOITOTYÖN LAATUA KÄSITTELEVÄÄN TUTKIMUKSEEN**, jos hän myös itse vapaaehtoisesti haluaa osallistua tutkimukseen. Lapsellani on halutessaan mahdollisuus olla osallistumatta tutkimukseen ja se ei vaikuta mitenkään hänen hoitoonsa sairaalassa.

Suostumuksen antaja:	**Suostumuksen vastaanottaja:**
______________________________ Tutkimukseen osallistuvan lapsen nimi	______________________________ Hoitajan nimi
______________________________ Lapsen syntymäaika	______________________________ Hoitajan nimen selvennys
______________________________ Lapsen vanhemman / huoltajan allekirjoitus	______________________________ Paikka ja aika
______________________________ Lapsen vanhemman / huoltajan nimen selvennys	
______________________________ Osoite ja puhelin	
______________________________ Paikka ja aika	

Tutkijan yhteystiedot:

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Puh: 02 7312109, 044 777 6529

Tässä paperissa olevat henkilö- ja yhteystietonne jäävät osastolle säilytykseen ja ne hävitetään asianmukaisesti tutkimuksen valmistuttua, eli yhteystietonne eivät ole tutkijan käytettävissä.

Appendix 18. Main quality category of nursing activities formed by the first principal component analysis (n=388)

Item no	Abbreviated items	Principal Component 1	Principal Component 2	Principal Component 3	Principal Component 4	Principal Component 5
32	Comforts	0.679				
30	Considers child's opinions	0.665				
29	Listens	0.655				
28	Protects intimacy	0.597				
37	Encourages child to ask questions	0.552				
27	Helps	0.530				
31	Encourages	0.524				
38	Takes account of child's food preferences	0.432				
39	Provides relief for pain	0.405				
44	Treatment		0.765			
45	Medication		0.739			
43	Reason for hospitalisation		0.652			
48	Moving in hospital		0.652			
47	Eating and drinking		0.650			
46	Procedures		0.450			
35	Cares for child together with parents		0.355			
36	Information that is easy to understand		0.321			
52	Leisure activities			0.868		
51	Going to school			0.814		
49	Duration of hospitalisation			0.657		
50	Home care instructions			0.431		
41	Helps with bathing				0.779	
42	Helps with toileting				0.756	
40	Helps with eating				0.668	
25	Plays with children					0.634
34	Encourages participation in care					0.609
26	Talks about interesting things					0.604
33	Informs child on what they can do					0.488
Eigenvalues, percentages explained and total variance (%) by components						
Eigenvalue		3.47	3.43	2.83	2.15	2.06
Total percentage and cumulative addition		12.41 %	12.26 %	10.11 %	7.67 %	7.34 %
Total percentage of principal component model						49.80 %

Appendix 19
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Vastaa kysymyksiin laittamalla rasti (X) sopivaan vaihtoehtoon tai kirjoita vastaus viivalle.

1. Olen
    a) tyttö
    b) poika

2. Olen __________ vuotta vanha

3. Tulin sairaalaan,
    a) koska siitä oli etukäteen sovittu
    b) koska loukkasin itseni
    c) koska tulin äkkiä kipeäksi

4. Olen nyt sairaalassa, koska minulla on ____.

5. Olen nyt ollut sairaalassa
    a) 1 yön
    b) 2 yötä
    c) 3 yötä
    d) 4 yötä
    e) 5 yötä tai enemmän

jatkuu

6. Sairaalassa,
    a) olen ollut huoneessa, jossa vain minä olen ollut potilaana
    b) olen ollut huoneessa, jossa on ollut myös muita potilaana olevia lapsia
    c) olen ollut huoneessa, jossa olen ollut yksin sekä huoneessa, jossa on ollut myös muita potilaana olevia lapsia

7. Olen aikaisemmin ollut sairaalassa yötä
    a) kyllä
    b) en
    c) en tiedä
    d) en muista

8. Vanhempani ovat olleet tällä kertaa kanssani sairaalassa
    a) koko ajan
    b) päivällä, mutta ei yöllä
    c) kun tulin sairaalaan ja kun pääsen kotiin

9. Minulla on ollut sairaalassa oma hoitaja
    a) kyllä, hoitajani etunimi on____
    b) ei
    c) en tiedä

jatkuu

Millaiset hoitajat Sinua ovat sairaalassa hoitaneet?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina olleet tällaisia.
Rastita 😐 naama, jos hoitajat mielestäsi ovat joskus olleet tällaisia.
Rastita ☹ naama, jos hoitajat mielestäsi eivät koskaan ole olleet tällaisia.

Hoitajani ovat olleet	AINA	JOSKUS	EI KOSKAAN
10. kilttejä	☺	😐	☹
11. taitavia	☺	😐	☹
12. kivoja	☺	😐	☹
13. hauskoja	☺	😐	☹
14. rehellisiä	☺	😐	☹

jatkuu

Appendix 19
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Mitä hoitajat ovat tehneet Sinun kanssasi?

Rastita ☺ naama, jos olet sitä mieltä, että hoitajat ovat aina tehneet kanssasi näin.
Rastita 😐 naama, jos hoitajat ovat joskus tehneet kanssasi näin.
Rastita ☹ naama, jos hoitajat eivät koskaan ole tehneet kanssasi näin.

Hoitajat ovat	AINA	JOSKUS	EI KOSKAAN
15. leikkineet ja/tai pelanneet kanssani	☺	😐	☹
16. jutelleet kanssani minua kiinnostavista asioista	☺	😐	☹
17. ymmärtäneet, että en halua olla ilman vaatteita muiden lasten ja vanhempien nähden	☺	😐	☹
18. kuunnelleet minua	☺	😐	☹
19. ottaneet mielipiteeni huomioon	☺	😐	☹
20. rohkaisseet minua	☺	😐	☹
21. lohduttaneet minua	☺	😐	☹
22. kertoneet, mitä voin ja saan itse tehdä sairaalassa	☺	😐	☹
23. antaneet minun itse osallistua omaan hoitooni	☺	😐	☹
24. hoitaneet minua yhdessä vanhempien kanssa	☺	😐	☹
25. huomioineet, mistä ruuista pidän	☺	😐	☹

Kiva, kun jaksat vastata!

jatkuu

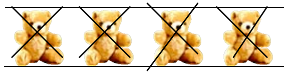
Laita rasti ruutuun, jos **ET OLE** tarvinnut hoitajien apua seuraavissa asioissa	AINA	JOSKUS	EI KOSKAAN
26. hoitaneet kipujani minulla ei ole ollut kipuja ☐	☺	😐	☹
27. auttaneet minua syömisessä en ole tarvinnut apua ☐	☺	😐	☹
28. auttaneet minua pesuissa en ole tarvinnut apua ☐	☺	😐	☹
29. auttaneet minua vessassa käynneissä en ole tarvinnut apua ☐	☺	😐	☹

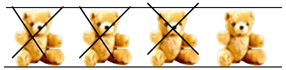
Mitä asioita ja kuinka paljon hoitajat ovat Sinulle kertoneet?

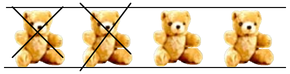
Hoitajat ovat mielestäni kertoneet minulle	TARPEEKSI	JONKUN VERRAN	EI LAINKAAN TARPEEKSI
30. miksi olen sairaalassa	☺	😐	☹
31. miten sairauttani hoidetaan	☺	😐	☹
32. lääkkeistäni	☺	😐	☹
33. toimenpiteistäni (kuten verikokeen tai röntgenkuvan ottamisesta)	☺	😐	☹
34. mitä voin syödä ja juoda	☺	😐	☹
35. missä ja miten voin liikkua sairaalassa	☺	😐	☹
36. kauanko joudun olemaan sairaalassa	☺	😐	☹
37. miten hoidan itseäni, kun pääsen sairaalasta kotiin	☺	😐	☹
38. milloin voin mennä kouluun	☺	😐	☹
39. milloin voin osallistua harrastuksiini	☺	😐	☹

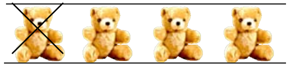
jatkuu

Mitä mieltä olet seuraavista asioista?

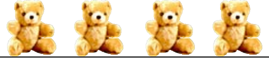
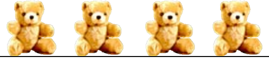
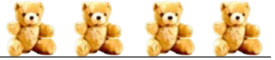
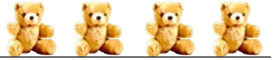
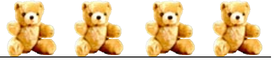
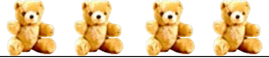

Rastita 4 nallea, jos olet asiasta täysin samaa mieltä.


Rastita 3 nallea, jos olet asiasta jonkin verran samaa mieltä.


Rastita 2 nallea, olet asiasta jonkin verran eri mieltä.


Rastita 1 nalle, jos olet asiasta täysin eri mieltä.
Vastaa joka kohtaan!

Sairaalassa

40. aikani on kulunut hyvin esimerkiksi pelaamalla, katselemalla videoita, lukemalla ja leikkimällä	
41. on ollut tarpeeksi kirjoja ja lehtiä	
52. on ollut tarpeeksi videoita ja pelejä	
43. on ollut tarpeeksi askartelua	
44. on ollut tarpeeksi leluja	
45. on ollut paikkoja, joissa olen voinut jutella ja leikkiä vanhempieni ja muiden vieraideni kanssa	
46. on ollut kodikasta ja viihtyisää	

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47. on ollut helppo löytää eri paikkoihin kuten vessaan tai leikkihuoneeseen	🧸	🧸	🧸	🧸
48. olen voinut olla yksin omassa rauhassa, jos olen halunnut	🧸	🧸	🧸	🧸
49. vanhemmistani on ollut minulle seuraa	🧸	🧸	🧸	🧸
50. sukulaiseni ovat voineet olla tarpeeksi kanssani	🧸	🧸	🧸	🧸
51. kaverini ovat voineet olla tarpeeksi kanssani	🧸	🧸	🧸	🧸
52. hoitajat ovat olleet tarpeeksi kanssani	🧸	🧸	🧸	🧸
53. muista potilaina olevista lapsista on ollut minulle seuraa	🧸	🧸	🧸	🧸
54. olen pelännyt yksinoloa	🧸	🧸	🧸	🧸
55. olen pelännyt pistämistä ja piikkejä	🧸	🧸	🧸	🧸
56. olen pelännyt hoitajia	🧸	🧸	🧸	🧸
57. olen pelännyt lääkäreitä	🧸	🧸	🧸	🧸
58. olen pelännyt kipua	🧸	🧸	🧸	🧸

jatkuu

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59. Minun mielestä kivointa sairaalassa on ollut

____

____

____

60. Minun mielestä ikävintä sairaalassa on ollut

____

____

____

61. Koulussa annetaan numeroita 4-10. Minkä numeron antaisit tällä kertaa hoidollesi sairaalassa? ____________________