Information exchange in paediatric care

Cover: Drawing of family by Josefin, 5 years of age

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To my loved ones

“There can be no keener revelation of a society’s soul than the way in which it treats its children.”

Nelson Mandela
Launch of Nelson Mandela Children’s Fund in South Africa
Mahlamba’ndlopfu, Pretoria, 8 May 1995
ABSTRACT

Information exchange is an essential component for all involved in the paediatric care encounter. Despite this, most of the research about information exchange concerns adults and the significance of the child’s existence in the encounter have not been given sufficient attention. Therefore, the overall aims of this thesis were twofold. Firstly, the aim was to identify, describe and generate concepts in information exchange between minors, parents/guardians and health care professionals in paediatric care situations. Secondly, the intention was to formulate a theoretical construction, a theory, of the phenomenon of information exchange in paediatric care situations.

This thesis is based on four studies. In studies I, II and III grounded theory was used according to Glaser and data have been analyzed using the constant comparative analysis method. Data have been collected through observations and medical records (I, II and III) and also with additional follow-up interviews (III). In study IV, at first a qualitative content analysis of Løgstrup’s ethical demand was conducted and, second, a simultaneous concept analysis of the findings from studies I, II and III and the findings from the qualitative content analysis was carried out. There were a total of 67 participants in the three observational studies: 28 minors (I), 24 parents/guardians (II) and 15 health care professionals (III), who exchanged information in different paediatric care encounters.

The information exchange interaction process was resolved by the minors “balancing the circumstances” (I), the parents/guardians used “firm handling” (II) and the health care professionals were “sharing and contributing the responsibility” (III). The qualitative content analysis of Løgstrup’s ethical demand provided the mediation and the social norms. The simultaneous concept analysis finally gave the advanced outcome to intergrade, which means to merge gradually with another through a continuous series of intermediates. At the same time as we intergrade in paediatric care, we protect the totality of minors, recognize the dependency of the parents/guardians and the social interplay by the health care professionals, the information exchange is improved. This thesis emphasizes the importance of health care professionals’ communication skills and the need for education and practice in this topic, in order to improve the information exchange with minors and their parents/guardians from an ethical viewpoint. The theory intergrade explains how this could be applied and implemented.
LIST OF PAPERS

This thesis for the doctoral degree is based on following four papers, referred to in the text by their respective Roman numerals:


II. Mårtenson, E., Berterö, C., & Fägerskiöld, A. Firm handling the information exchange interaction by parents/guardians in paediatric care – An observational study. (Submitted.)


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# ORIGINAL PAPERS I-IV
INTRODUCTION

Children aged 0-17 years represent almost one fifth of Sweden’s population, approximately two million persons, and 1.1 million families living in Sweden have children between these ages (Statistiska centralbyrån, 2007). Children’s human rights to receive information and participate in decision-making makes it necessary for health care professionals to be educated in child development and in communication, as in information exchange (Rushforth, 1999). Information exchange is considered to be the central point of a medical encounter (Cegala, et al., 1998). Information exchange is a possibility and a necessity to be active and be able to participate in one’s own health care. This is most valuable to our children in order to become independent and responsible adults with absolute integrity in our society.

It is important to discuss with and listen to the children in paediatric care but it becomes humiliating if there is no commitment to what they actually say (Hall, 2005). Insufficient, misunderstood or non-existent information exchange is also considered to be an important risk, due to implications for the safety of the patient, both in children and adults (Socialstyrelsen, 2003a; 2003b). The child ought to be respected, as should their parents (Waterston, 2005).

Children are an exposed and vulnerable group in society and they should be treated as being more vulnerable than adults (The Children’s Ombudsman, 2007; Westman, 1999). When children are in paediatric care, they have special needs because of their continuous development (Bearman, et al., 2005; Price, 1994). In an encounter, there is always a risk of relying on the other person as these expectations of trust can be ruined. Our life is characterized by encountering one another with trust. Trust can be seen as an invitation to be listened to, a wish to be listened to and a need to be taken seriously (Løgstrup, 1997). Most research in the area of information exchange is about adult communication and the implications of the child’s presence in the medical encounter have been ignored (Tates & Meeuwesen, 2001; van Dulmen, 1998). This thesis emphasizes the importance of knowledge of information exchange in paediatric care from the view of all involved participants: children, parents/guardians and health care professionals. Information exchange is also analyzed from the perspective of the ethical demand (Løgstrup, 1997).
BACKGROUND

In this thesis, information exchange is used to describe the interchange of information between the participants in the paediatric care encounter through a rights based perspective. These three pillars: information exchange, paediatric care and rights are interrelated and should not be separated. In the following sections other terms are used instead of information exchange when referring to other studies. The mesh term communication used in Medline/PubMed is defined as “the exchange or transmission of ideas, attitudes, or beliefs between individuals or groups”. Consultation is used to illustrate either the act of consulting or an encounter (Merriam – Webster Online Search), depending on the present situation.

Information exchange

There is a general agreement that information exchange is at the heart of the medical consultation (Cegala, et al., 1998). It seems adequate to consider the health care professionals’ skill in communication as being as important as other clinical skills in caring (Alexander, 2001). Physicians need information from patients to determine an accurate diagnosis and effective treatment plan, and patients need information about their medical problem and the rationale and procedures for its treatment. Information exchange consists of seeking, giving and verifying information (Cegala, et al., 1998).

The information process is fundamental in making it possible for children to participate in their own care. Making it easier for the children to make small choices in their care may facilitate and enable them to make decisions (Brook, 2000). The principle of the practise of information sharing is to respect and protect the children and to inform them at their own tempo. The policy is to talk with the children and not to them, as information is to be shared with them and their families and not just given to them. The partnership is to share information between child, parent and health care professional (Brook, 2000; Coyne & Crowley, 2007). Information exchange in paediatric care involves providing understandable information to child and parent, asking them for information and advising them how and where to obtain information. This process is assessed as being important and related to child and parental

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satisfaction with their care (King, et al., 1996). Information, prior to undergoing a clinical diagnostic procedure, is assessed as important to children in an interview study of 23 children (6-11 years) (Runeson, et al., 2007). Though the children received information from one or several sources as; nurse or physician at a former visit, parents, letter received, former information visit and from a nurse on the actual day, the conclusion was that as a group these children were not well informed. Actually, none of the children could give a reasonable explanation of what was going to occur during the visit at the paediatric day care unit. Fourteen of the 23 children said that they did not participate in any decisions during the visit, but most of the children were convinced that the physician and parents would act in their best interest (Runeson, et al., 2007). This lack of involvement and participation is also to be seen in a study by van Dulmen (1998). Out of 302 outpatient encounters, the children’s (age 5.3 years of average) contribution to the encounter was limited to 4 percent and only 13 percent of the medical information was directed toward them. Furthermore, in 110 encounters, (36 %), the child did not participate at all (van Dulmen, 1998).

Children narrated their need for consultation and information in Coyne’s study (2006) of 11 children, (7-14 years), ten parents and 12 nurses: to facilitate the understanding of their illness, participate in their own care and to get ready for treatment. The children sought information actively to cope with their hospitalization. It seemed as though the children felt pleased when they were informed and consulted about their care. Some children noted that the physician ignored them completely, or discussed them with other physicians, or their parents, in front of them but without involving them (Coyne, 2006). In a study of parents and their children, (9-21 years), perspectives on physician communication in paediatric palliative care information exchange was one of the most thoroughgoing findings (Hsiao, et al., 2007). The desired physician’s information exchange was explained thus: ability to listen, talks in a clear and simple manner, explains properly, and makes information completely available to both children and parents. Parents find information exchange, involving mutual trust, with health care professionals to be essential when their child (1.4–9 years) needs care (Nuutila & Salanterä, 2006). It was important to the parents that they received information from the very beginning, because knowledge helped them understand what had happened. Initially they received a lot of information, much more than they could embrace. Later on, the parents needed to know if the way they solved the problems was correct, at the same time they needed new information continuously, the parents needed to feel reinforced. At this time the
information changed to a two-way flow between the parents and health care professionals, as in information exchange (Nuutila & Salanterä, 2006).

Brykcyńska (1987) discusses information in the ethical practise of nursing and stresses the importance of giving and receiving information in order to make facts available to both parties. In an observations study of 35 parents of 24 children, (5 months-18 years), the parents’ need for open communication was highlighted, because some parents are not willing or capable expressing their opinion, due to changes in their parental roles (Hallström, et al., 2002). Levetown and the Committee on Bioethics (2008) emphasizes communication in paediatric practice as a most important skill on the part of the paediatricians, which must be trained by use of different training tools, such as interactive discussions, parent – panel discussions, using simulated patients, video feedback etc. Health care communication is central for paediatricians in creating a trustful relationship with the child and their family, as well as an ethical obligation towards them (Levetown & the Committee on Bioethics, 2008). Communication training provided to health care professionals is assessed as being important in order to improve paediatric hospital care (Kemmner, 2007; van Dulmen, 1998).

**Paediatric care**

There have been changes in paediatric hospital care for both children and their parents in the most recent decades. In the early days, the child was separated from his/her parents while nowadays the parents participate and sometimes even feel totally responsible for the care of their child (Coyne & Cowley, 2007). Concurrently, the development of the right of the child to participate in decision making in their own care may imply that the grown-up might have less power than previously (Alderson & Montgomery, 2001). At the same time, the child’s existential need of being close to his/her parents is shown as loyalty towards the parents and the child thereby adapts the dialogue to what is accepted by the parents (Hindberg, 2003). This loyalty and dependency is to be seen to be in agreement with Løgstrup’s ethical demand (1997); how we are mutually dependent on one another.

Paediatric care is governed by laws and statutes, which regulate the obligations to the child. This stance of policy is to be seen in the Swedish Health and Medical Service Act (SFS 1982:763), which states that care should be provided with respect for the equal dignity of all human beings and for the dignity of the individual (Swedish Codes of Statutes, 1982). It also says that
care and treatment shall, as far as possible, be designed and conducted in consultation with the patient. The patient shall be given individualised information concerning his/her state of health and the treatment methods available.

A child is not to be seen as a small adult and health care professionals need specific skills to work in paediatric care with children and their families (Bearman, et al., 2005). The services for children and young people should be centred on the needs of the young person, on high quality, orientated toward the family, equitable and non-discriminatory, inclusive of the individual’s needs, empowering, result oriented and evidence-based, coherent in design and delivery, supportive and respectful and community enhancing (Department of Health, 2003a). Paediatric care should integrate the child’s particular needs and the needs of the child’s family. The child and their family should be treated with respect and should be informed, so that they are able to understand and cope with the illness and its related treatment. It is also important for the child to participate in their care and, where it is possible, make their own choices (Department of Health, 2003b).

Health care professionals have a professional obligation to do that which is considered to be right (Holm, 1997). In Sweden the Swedish Association of Paediatric Nurses together with the Swedish Society of Nursing (Sjuksköterskor med inriktning mot barn och ungdom & Svensk sjuksköterskeförening, 2008), has developed a competence description for paediatric nurses. One of the areas of competence concerns encounter, information, participation and education. It is stated, among others, to talk to the child primarily, to make sure that the child and the family understand given information and that the caring encounter should be respectful and empathetic. The International Council of Nurses (ICN) declares in the ICN Code of Ethics for Nurses that nursing care must be respectful and unrestricted by considerations of, among other things, age. The nurse shall also guarantee that the individual will be given adequate information (ICN, 2006).

Good clinical practice in paediatric care prescribes acting in the best interests of the child (Kurz, et al., 2006). Guidance on this can be received from the United Nations Conventions on the Rights of The Child, (UNCRC) (United Nations, 1989). Children have the right to be told the truth, by the paediatrician, about their medical conditions, about treatments and a prediction of the course of the disease. The paediatrician should have an empathetic approach, as the basis of each medical communication (Kurz, et al., 2006). The Standing Committee of European Doctors (2006) adopted the policy
to provide the young person with sensitive and careful guidance and support throughout their illness. Both the young person’s right to be involved in healthcare decisions, as well as the role of parents or guardians is essential. The duties of a physician is, according to the World Medical Association, WMA, International Code of Medical Ethics (2006), among other things, to respect the rights and preferences of patients, colleagues, and other health professionals and to act in the patient's best interest when providing medical care.

Children’s views of how good children’s nurses should be were identified in an interview study by Randall et al. (2008). Paediatric nurses should encounter them in a respectful manner and also have an ability to interact with them. It appeared that the children described a caring, patient, and calm nurse who was willing to advocate the children’s rights. “They should speak to you nicely and explain what they are going to do, and why. They need to take their time and listen to you. Important to be sociable and have non-medical chat.” (Randall, et al., 2008, p. 24) These findings correspond with the concept partnership nursing explored by Lee (2007), where nurses are promoted to work in partnership with children and their families. Categories that emerged from the interview study with experienced children’s nurses were: attitudes, respect for family, communication, parental understanding, effective partnership, all parties satisfied and improved well-being (Lee, 2007).

Parents’ experiences of participation in their hospitalized child’s care were discussed by Coyne (1995). Aspects which obstructed the parents’ participation were, among other things, feelings of redundancy and lack of information. The parents wanted to participate in the care because of their considerations for their child (Coyne, 1995). In a later study by Coyne and Crowley (2007), a critical view of the reality of the partnership in care is added, as nurses seem to be dependent on the parent’s contribution in care as well as expecting the parents always to be available as informal carers in the organisation.

Nursing staff might have a tendency to control parental participation in paediatric care and this attitude can make the parents feel disempowered (Corlett & Twycross, 2006). These stressful emotions are worsened by poor communication and lack of information sharing. Brykcyńska (1987) promotes the ethical responsibility of working with the “forgotten colleagues” (the children) as partners-in-care and towards their shared goals. Paediatricians ought to support a rights-based approach in paediatric care and this approach must be included in the education and training of the paediatricians (Waterston, 2003).
Rights

Children’s rights are the basic human needs for life, growth, and development and not abstract and idealistic desires (Reading, et al., 2009). The Universal Declaration of Human Rights (United Nations General Assembly, 1948) states in article 1 that “All human beings are born free and equal in dignity and rights”. Rights are equal entitlements for all members of the human family to respect their worth and dignity (Alderson, 2000). Rights are always and only applicable in a social situation (Flekkøy & Kaufman, 1997), such as in relationships. Children are in a state of integrity, with expectations of having their human rights respected, just as much as if they were an adult. Integrity stands for an unreduced wholeness and the right to speak and to have an opinion and that it matters what is said. Integrity can be invaded or respected but never replaced by someone else (Bischofberger, 2004). Autonomy means having the power to make free choices, unconstrained by external agencies (Beauchamp & Childress, 2001). Children and young people need information require respect and should be given the possibility of expressing their opinion (Waterston, 2003).

Individual rights originate from the reality that human beings are vulnerable and the most vulnerable persons are children (Westman, 1999). The most basic right of children is tender and protecting parenting, as children need to be protected. Parents are liable for the upbringing and activities that impart knowledge to their children. On the other hand, children have a mutual commitment to respect and cooperate with their parents. Becoming a parent is an important adult development and the development as parent is contemporaneous to the development of children. Children are the future of society and parents prepare their children to become adult citizens and this highlights the parents’ importance to society (Westman, 1999). Adults have different perspectives about how to achieve the best interests of the child in a study of Alderson (1992), where 120 children, (8-15 years), their parents and 70 health care professionals were interviewed about their opinion of when children have sufficient understanding to be able to make decisions about proposed surgery. The answers were divided into the three perspectives: parentalists, protectionists and libertians. Parentalists think that the parent is the most suitable person to decide for their child, the protectionist considers the health care professionals to be the most appropriate and, finally, the libertians believe that children should exercise their rights as soon as they are old enough (Alderson, 1992). The UNCRC supports the parents in their parenting role in articles 5 and 18 (United Nations, 1989).
In Sweden, the UNCRC permeates all decision making concerning children in government authorities, county councils and local authorities (The Children’s Ombudsman, 2005). Although Swedish legislation agrees with fundamental features of the UNCRC, there are differences. Swedish acts emphasize the duty of parents and society instead of the rights of the child. The Act on the Children and Parents Code (SFS 1949:381) regulates rights and obligations of the person in custody of a child (Swedish Code of Statutes, 1949). Swedish courts of law are not allowed to pass judgement concerning medical treatment in an individual case; this is in contrast to the UK and USA (Rynning, 1994).

The European Association for Children in Hospital (EACH) associates with the thoughts of the UNCRC (1989) and defines a set of guidelines for children welfare within a hospital setting in the EACH Charter for Children in Hospital (EACH, 1988). The EACH Charter consists of ten articles, where article four is about the child’s and parents’ right to be informed in an understandable manner (EACH, 1988). In a survey study by Migone et al. (2008), the perceived adherence of the EACH Charter (EACH, 1988) in a paediatric hospital was conducted. The sample consisted of 100 parents, 50 children, (9-17 years), and 102 health care professionals (61 nurses and 41 paediatricians). One result was that only 50 percent of the nurses and 59 percent of the paediatricians encouraged the children to ask questions. Another result was that 43 percent of the parents and 70 percent of the children felt that there was a lack of information due to side effects of medication. The Nordic Association for the Needs of Sick Children, (NOBAB), is an umbrella organization for the Swedish NOBAB (1980), where there is an ongoing project about safe children in health care.

Information exchange is related to articles 12, 13 and 17 in the UNCRC (United Nations, 1989). In a study by Noyes (2000) of 18 ventilator dependent young people these rights were not always supplied, as results show that not all the young people had access to a communication system corresponding to their needs. Thereby they were not able to express their opinion freely as stated by article 12. Neither did they always have access to adequate information in agreement with article 13, and were thereby frequently excluded from making important decisions in their own lives, in contradiction to article 17 (Noyes 2000). Nurses must consider in everyday practise how to protect a child’s right and this is to be seen as a balancing act on the part of the children’s nurse (Doyle & Maslin-Prothero, 1999). Paediatric nurses become most important in the implementation of the child’s rights, because these rights are only theoretical until they are put into practice in paediatric care.
CONCEPTUAL FRAMEWORK

In this thesis, the ontological approach is based on logical empiricism, where knowledge is reached through both methodological research and theory development (Patton, 2002). Epistemologically the attitude towards knowledge reached is based on the human understanding that we always interact with each other and this interaction makes us vulnerable. This vulnerability is to be handled within the ethical demand (Løgstrup, 1997), the significance and heart of care, to take care of another person without expecting anything in return.

The term language used in this thesis is about the spoken words and sentences but also about the manner of communication, verbal and non verbal, as in interactions (Merriam – Webster Online Search).

Interactions

Interaction is a mutual or reciprocal action and this is relevant to information exchange in paediatric care. To be informed is a way of getting to know and Vygotskij (1978) believes that knowledge is a direct result of social interaction and that everyday life is built on empirical knowledge. Vygotskij (1978) values the notion of “able instruction”, someone who has more knowledge and experience, shares it with others, to reach the zone of proximal development. Development of language and thoughts is dependent on a social relation and how a potential and optimal level of development is stimulated by others (Vygotskij, 1978). This is what might happen in a medical encounter, the health care professional encounters and exchanges information with the child, so that the child can reach a higher level of understanding and thereby participate in the nursing care (Rushforth, 1999). In an ethnography study of 49 inpatients, (6 – 16 years), by Lambert et al. (2008), the nature of communication between children and health care professionals was named “visible-ness”. Visible-ness consisted of the two polar ends, “being overshadowed” and “being at the forefront”. The first could be understood in the context of “children should be seen but not heard”. In “being overshadowed” the children were outside the communication while in “being in the forefront” they were in the lead of the communication.
We must always express ourselves and interact through something intermediary, such as culture and norms, and it is the language that is the mediator (Løgstrup, 1997). In an encounter, there are discrepancies between the experiences and language usage between children and adults and thereby the children sometimes need guidance from the adults (Vygotskij, 1978). This is visualized in a study of eight inpatient children in Korea, (5-6 years), where the children remained passive participants in the interaction. The conclusion was that nurses needed to help the children to interact actively (Shin & White-Traut, 2005).

Information will be shared with the child and family in an interactive process (Brook, 2000). Also the consultation, where the attitude of all involved is considered before the medical decisions are made, is a social interaction (Nicholson & Clarke, 2007). Parents identified their experiences with nurses who cared for their inpatient children as interactions, which were influenced by the expectations they, as parents, had of the nurses (Espezel & Canam, 2003). The parents found the interactions mostly positive but they did not think they involved collaborative relationships.

Tates et al. (2002b) describe the interaction during information exchange as what is said, how it is said and in what order and have used the Roter Interaction Analysis System (RIAS), which is a method of coding the interaction between doctor and patient during a medical visit (RIAS, 2008). Tates et al. (2002b) classified adult behaviour in terms of supportive versus nonsupportive to children’s (4-12 years) participation in the medical interaction. Parental manners influence the physician in shifting from a supportive to a non-supportive behaviour towards the child. When parents ask a lot of questions and express emotional concerns, physicians have to focus on the parent instead of the child. Tates et al. (2002a) explored the communication in the doctor-parent-child triad and in terms of child centred and family focused. The participating 106 children (4-12 years) were accompanied by their parents and were videotaped when visiting the doctor. The results indicate the medical interview as having two main purposes – information sharing and a possibility of creating a good interpersonal relationship. Through encouraging children’s participation, physicians show that collaboration in the medical encounter is desirable and indicates children as being autonomous participants.

Crossley and Davies (2005) constructed an assessment model of the doctor-patient interaction, based on content analysis of relevant literature and also consensus group discussions with paediatricians. This model aimed to develop an assessment tool of interaction within consultations involving
children. Three parallel rating instruments were developed, (younger children 7-11 years, older children aged 11-16 years and adults older than 16 years), which intended to assess how adults and children rated the doctor-patient interaction (Crossley, et al., 2005). As an example of patient-centeredness, one item for parents was: “How much was the doctor interested in your child’s point of view when he or she was asking questions?”, and the corresponding item to older children was: How much was the doctor interested in your point of view when he or she was asking questions?”(Crossley, et al., 2005, p. 821). The method was found to be useful in in-training assessment and seen as important in order to give feedback and improve the quality of paediatricians’ interactions.

Symbolic interaction is a natural type of data that occurs in interaction (Glaser, 2005). Symbolic interactionism is about human beings acting on the basis of the meaning symbols have for them, for example words. The meaning comes out of the social interaction and is handled in an interpretive process. Through the language in a social interaction, a person can understand relations and processes. Communication is a subsequent phase of interaction. A decision is made between persons but also within a person (Blumer, 1986).

**Løgstrup’s ethical demand**

The Danish philosopher and theologian Løgstrup developed interdependence as an ethical theory on account of human beings always being in relationships with one another (Løgstrup, 1997). When a situation demands something from a person, that person becomes involved in an ethical decision: that is the ethical demand. The ethical demand involves two principles. Firstly, human beings are involved with each other’s lives and because of that involvement they have to care for each other. Secondly, our life is to be seen as a continuous gift. The one-sidedness of the ethical demand is that human beings can never demand something in return for what they do for another person, as you never can claim anything from a gift. The ethical demand is also considered to be a silent demand, as it is not defined how it can be fulfilled.

Human beings are mutually dependent on each other and human beings use power over each other in an encounter (Løgstrup, 1997). Løgstrup talks about interdependence in the mutual encounter but does not use the expression participation explicitly. Taking part and being involved in the mutual encounter might be similar to interdependence. The ethical demand in the mutual encounter is to be seen as a requirement to answer the other person’s wishes and needs, the desire to do what is the best for the other
person. If the health care professional-patient-relation becomes unequal, there is a risk of mistreatment of the person in need.

It is important to be observant of the health care professional’s own ideology when working in health care, so ideology does not become the rule. Instead the health care professional has to take into account the other person’s needs. When rules and principles have taken over the nursing situation, the vulnerability of the other person will not be respected (Martinsen, 2006). If the health care professionals do not act, as when neglecting the other person’s needs, it is maltreatment and the ethical demand is not being answered (Løgstrup, 1997).

The ethical demand is to take care of another person without taking over the other person or the other person’s own responsibility. Løgstrup (1997) also talks about the antithesis autonomy and dependence, which are basic conditions. This makes it possible for a person who is totally dependent on others to be fully autonomous, as shown in the study by Noyes (2000), where ventilator-dependent children, 6-18 years, explained how they wanted to decide for themselves.

A person who trusts expects someone else to fulfill his or her expectations. Our life is characterized by encountering one another with trust; this is what Løgstrup describes as a sovereign and spontaneous life manifestation. All communication and interactions are based on mutual trust. The sovereign and spontaneous life manifestations are the way human beings meet each other naturally, unless they actively decide to act in a different way, because human beings do not distrust each other unless they think they have reason to do so. Løgstrup (1997) says that we are each other’s life and destiny and this result in the way human beings interact with each other influencing how they perceive their world. The world can become larger or smaller, bright or drab, rich or dull, threatening or secure, according to this influence.

Martinsen (2006) says that, without trust, we cannot meet each other with generosity in the nursing situation. Paediatric care needs to be based on mutual respect and trust, as it concerns the most vulnerable persons in society (Brook, 2000). Nurses can handle this vulnerability by being clinical and act in a professional way in health care. The vulnerability is also to be handled in a mutual way, as the patient is protected by the professionals performance and the nurse is protected by his/hers skills and experience (Martinsen, 2006).
AIMS

The overall aims of this thesis were twofold. Firstly, the aim was to identify, describe and generate concepts in information exchange between minors, parents/guardians and health care professionals in paediatric care situations. Secondly, the intention was to formulate a theoretical construction, a theory, of the phenomenon of information exchange in paediatric care situations.

The specific aims were to:
1. Identify, describe and generate concepts regarding the exchange of information between children/young people and healthcare professionals in paediatric outpatient settings (I).
2. Identify, describe and conceptualize how parents/guardians resolved their main concern in information exchange with health care professionals in paediatric care situations involving their minors (II).
3. Identify, describe and generate concepts regarding health care professionals’ information exchanges with minors and/or their parents/guardians in paediatric caring situations (III).
4. Contribute to nursing science by utilizing advancement of concepts and to provide a theoretical perspective of the phenomenon information exchange in paediatric care (IV).

A child is, according to the UNCRC (United Nations, 1989), every person up to 18 years old. In this thesis, minor is used instead of child, because of the fact that a minor is a person who has not reached the age at which full constitutional rights are accorded (Rynning, 1994). In study I, minor is changed to children/young people because of policy of the journal of publication. The parent/guardian is the person responsible for bringing up the minor, whether they are the biological parent, the foster parent, stepparent or the grand parent. Paediatric nurses, enrolled nurses and paediatricians are named health care professionals in this thesis. Care situations are all situations that occur on an outpatient paediatric unit, as for example examination, blood test taking, case history taking, preparation for x-ray etc.
METHODS

The data in this thesis have been analysed and developed in several different ways. In the three grounded theory studies I, II and III, empirical data were inductively conceptualised with the constant comparative analysis method (Glaser, 1978). The qualitative content analysis (Mayring, 2000) structured Løgstrup’s ethical demand (1997) into concepts and components to be used in the next following study, IV. Finally, in study IV the concepts were analysed and compared due to differences and similarities according to the simultaneous concept analysis (Haase, et al., 2000).

In total 67 participants

<table>
<thead>
<tr>
<th>Study I</th>
<th>28 minors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data:</td>
<td>76 observations and 20 medical records</td>
</tr>
<tr>
<td>Analysis:</td>
<td>Constant comparative analysis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study II</th>
<th>24 parents/guardians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data:</td>
<td>37 observations and 5 medical records</td>
</tr>
<tr>
<td>Analysis:</td>
<td>Constant comparative analysis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study III</th>
<th>15 health care professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data:</td>
<td>25 observations, 10 medical records and 15 follow-up interviews</td>
</tr>
<tr>
<td>Analysis:</td>
<td>Constant comparative analysis</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Study IV</th>
<th>Transcripts and text</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data/findings:</td>
<td>from studies I, II, and III and from the qualitative content analysis of Løgstrup’s ethical demand</td>
</tr>
<tr>
<td>Analysis:</td>
<td>Simultaneous concept analysis</td>
</tr>
</tbody>
</table>

Figure 1. Study design
Grounded theory

Grounded theory was formulated by Glaser and Strauss (1967) and elaborated by Glaser (1978). It is an inductive general method, where theory is generated from systematic research. Theory consists of conceptual categories, which are related to each other as an explanation of the way the participants resolve their main concern in a substantive area (Glaser, 1978; Glaser & Strauss, 1967). This grounded theory is named substantive theory as it is developed for a substantive or empirical area (Glaser, 1978), as in this thesis in paediatric care. Grounded theory can be used with either qualitative and/or quantitative data, as all is data (Glaser, 2001; 1998).

While grounded theory can be used as a systematic method to conceptualize behaviour, observational studies of information exchange in the context of paediatric care are relevant to the method, as theory comes from empirical data. It is most challenging to transform the data: field notes from observations, medical records and follow-up interviews, the description, to the more theoretical level, the concept (Glaser, 2002). The goal of grounded theory is to achieve at least the third level of concept: firstly, collecting the empirical data, secondly, generating categories, and thirdly discovering the core category, which organises the categories that continually solve the participants’ main concern (Glaser, 2002).

The use of writing sequences in the manuscript, to confirm the category to the reader, is problematic. The discrepancy between the descriptive level in the sequence and the theoretical level of the category causes discussions and doubts on the part of the reader. This makes it even more important to write and explain in a most accurate way and be stringent. Glaser (2001) explains it like this: “GT is applicable to the participants as an explanation of the preponderance of their behaviour which is how they are resolving their main concern, which they may not be aware of conceptually, if at all. It is just what they do! GT is not their voice: it is a generated abstraction from their doings and its meaning which are taken as data for the generation” (p.11). Grounded theory is conceptual and not interactional, but it is natural that symbolic interactionism occurs in interaction (Glaser, 2005).

The constant comparative analysis method verifies the participants’ main concern and is where the theory is generated (Glaser, 1978; Glaser & Strauss, 1967).
Qualitative content analysis

Qualitative content analysis is a technique for systematic text analysis (Mayring, 2000). Krippendorff (2004) defines content analysis as the use of a replicable and valid method for making specific inferences from text. It can be used either alone or in conjunction with other methods. All sorts of recorded communication can be used, as for example field notes of observations, medical records, transcripts from interviews and documents such as books (Krippendorff, 2004). In study IV, a structuring content analysis (Mayring, 2000) has been conducted on Løgstrup’s ethical demand (1997) in order to extend new knowledge.

The goal of qualitative content analysis is to reduce the material into the smallest parts, textual units. The rules of analysis are that the material is to be analyzed step by step and to organise the material into content analytical units. The research question decides the aspects of text interpretation (Mayring, 2004). The specific method, structuring content analysis, used in this thesis analyses the text according to a previously stated research question and the purpose is that the exact formulation of definitions will structure the task very precisely (Mayring, 2004).

Simultaneous concept analysis

The strategy of simultaneous concept analysis uses consensus group discussions and develops matrices with interrelated concepts simultaneously (Haase, et al., 2000). Concept analysis was developed by Wilson (1963) and introduced to nursing by Walker and Avant (1988). Simultaneous concept analysis is an addition to the process of explaining. The individual concepts are analyzed and attended by a critical assessment of interrelated antecedents, defining characteristics and outcomes, and insight into existing relationships. Haase et al. (2000) find the interrelation between concepts just as important as the concept itself. Simultaneous concept analysis was chosen as the method in this thesis because it could answer the research questions and develop a process model of information exchange in paediatric care in study IV. The method is described as guidelines in nine steps, and the steps are intertwined with one another and go back and forth. The simultaneous concept analysis strategy highlights concepts in care as complex and interrelated. Because these interrelationships exist, these concepts cannot be analyzed in isolation.
Settings

The observations were performed at three paediatric outpatient units at a university hospital in Sweden; the paediatric day care unit, the paediatric neuro-urology and bowel disorders unit (PNUT) and the paediatric diabetic clinic during the years 2005-2007. The numbers of visits at the different units, during the years 2006-2007, are listed in table 1. It should be noted that in 2005 the number of visits was not specified into the separate units. The numerals are from local information at the university hospital.

Table 1. Number of visits per unit and year

<table>
<thead>
<tr>
<th>Paediatric outpatient unit</th>
<th>2006</th>
<th>2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paediatric day care unit</td>
<td>2530</td>
<td>1954</td>
</tr>
<tr>
<td>PNUT</td>
<td>672</td>
<td>1204</td>
</tr>
<tr>
<td>Paediatric diabetic clinic</td>
<td>1320</td>
<td>1167</td>
</tr>
</tbody>
</table>

The units were situated alongside the same corridor (Figure 2). The observations were performed in the surgeries, the treatment rooms, the waiting rooms, on the ward and in the conference room and also in the corridor. The paediatric day care involved a variety of different treatments, examinations and preparations due to subsequent examinations of the minors at other units in the hospital. At PNUT, the care consisted of different paediatric urology and bowel care treatments and examinations. The diabetic clinic cared for minors with diabetes.

The health care professionals were paediatric nurses, paediatric enrolled nurses and paediatricians. Some of the paediatric nurses were specialized in urotherapy, oncology or diabetes. The paediatric enrolled nurses had special areas of paediatric care. The paediatricians attached to the units were specialized in oncology, urology, enteropathy or diabetes. All health care professionals were experienced in participating in research in one way or another.
Figure 2. Settings

1. Treatment room
2. Waiting room
3. Doctors office
4. Surgery
5. Ward
6. Conference room

- Places where the observations were conducted
Sample

All observations in the three studies were related to minors aged 10 - 17 years. A rationale for the lower age limit of ten years is that minors are according to a most cited study by Weithorn and Campbell (1982), considered to be able to participate in decision making concerning their own health care from the age of nine. This age limit, from the point of view of being able to give informed assent to clinical research, is also confirmed by Ondrusek et al. (1998).

Inclusion criteria for the informants in the three observational studies I, II and III were to be: (I) minor aged ten to 17, (II) parent/guardian to minor aged ten to 17 and (III) health care professional in paediatric care situations with minors aged ten to 17. There were two declinations to participate in the three studies, as one minor and one health care professional did not wish to participate.

When using the grounded theory method in a study, it is not possible to say in advance how many participants are needed to achieve saturation in the categories. Saturation means that no additional data are found whereby the researcher can develop the properties of the category; the similar instances happen over and over again (Glaser & Strauss, 1967). The paediatric outpatient units were selected to enable variation in the participants’ experiences, such as the minor’s various diseases and diverse examinations, and thereby the parents/guardians and health care professionals’ various experiences. The aim was to achieve saturation. Saturation was achieved at observation 62 (I), observation 32 (II) and at observation 17 (III), respectively. The sample was strategic in as much as there were boys and girls in each age-group and they were distributed among the different units. As the observer decided who should participate next and thereby tried to fill what was possibly missing, so called theoretical sampling, the categories emerged (Glaser, 1978).

Participants

There were a total of 67 participants in the three studies: 28 minors (I), 24 parents/guardians (II) and 15 health care professionals (III) (Figure 1).

The observed participants in study I were the 28 minors, where the minors exposure and vulnerability is visualised in the variety of diagnoses or examinations (table 2). The number of previous visits the minors had made to the unit varied between 0 and 69, the total time period of observation was 5 -
244 minutes and the total number of observations during the visit was 1-7 times.

**Table 2.** Characteristics of the 28 minors and the 76 observations in study I.

<table>
<thead>
<tr>
<th>Visit¹</th>
<th>Diagnosis or examination</th>
<th>Time²</th>
<th>Number³</th>
</tr>
</thead>
<tbody>
<tr>
<td>46</td>
<td>Systemic Lupus Erythematosus</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>0</td>
<td>Glomerulonephritis</td>
<td>39</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Renal agenesi</td>
<td>54</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>Incontinence</td>
<td>63</td>
<td>7</td>
</tr>
<tr>
<td>21</td>
<td>Type 1 diabetes</td>
<td>47</td>
<td>4</td>
</tr>
<tr>
<td>24</td>
<td>Type 1 diabetes</td>
<td>33</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>Myelomeningocele</td>
<td>121</td>
<td>4</td>
</tr>
<tr>
<td>0</td>
<td>Lumbar puncture</td>
<td>72</td>
<td>6</td>
</tr>
<tr>
<td>26</td>
<td>Kidney transplanted</td>
<td>56</td>
<td>6</td>
</tr>
<tr>
<td>0</td>
<td>Pyelonephritis</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>69</td>
<td>Type 1 diabetes</td>
<td>65</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Short bowel syndrome</td>
<td>28</td>
<td>1</td>
</tr>
<tr>
<td>31</td>
<td>Type 1 diabetes</td>
<td>39</td>
<td>3</td>
</tr>
<tr>
<td>1</td>
<td>Nocturnal enuresis</td>
<td>29</td>
<td>2</td>
</tr>
<tr>
<td>39</td>
<td>Relapsed Acute Lymphoblastic Leukaemia</td>
<td>29</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>Ependymoma</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>22</td>
<td>Type 1 diabetes</td>
<td>90</td>
<td>3</td>
</tr>
<tr>
<td>1</td>
<td>Renal scan</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>32</td>
<td>Lazy Bladder</td>
<td>244</td>
<td>5</td>
</tr>
<tr>
<td>1</td>
<td>Nephritis</td>
<td>46</td>
<td>4</td>
</tr>
<tr>
<td>0</td>
<td>Renography</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>0</td>
<td>Leukocyte scintigram</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>55</td>
<td>Acute Lymphoblastic Leukaemia</td>
<td>14</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Hypertension</td>
<td>35</td>
<td>1</td>
</tr>
<tr>
<td>41</td>
<td>Nocturnal enuresis</td>
<td>23</td>
<td>2</td>
</tr>
<tr>
<td>0</td>
<td>Computerized Tomography brain</td>
<td>15</td>
<td>1</td>
</tr>
<tr>
<td>61</td>
<td>Type 1 diabetes</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>13</td>
<td>Type 1 diabetes</td>
<td>40</td>
<td>3</td>
</tr>
</tbody>
</table>

¹ The minor’s previous number of visits to the unit
² The total time of observation of the minor in minutes
³ The total number of observations of the minor during the visit
In study II, 24 parents/guardians of 20 minors were observed; four of the minors were accompanied by both of their parents/guardians. The minors had visited the unit between 0 and 55 times before, the total observation time was between 5 and 114 minutes with the number of observations during the visit being 1 – 5 times. There were 18 female and six male parents/guardians.

Fifteen health care professionals were observed in study III. After the observation they all completed a follow-up interview. The 12 minors had visited the unit 2 – 50 times earlier, the observations lasted 5 – 170 minutes and the number of observations during the visit was 1 – 7 times. The health care professionals consisted of nine paediatric nurses, two enrolled nurses and four pediatricians. The health care professionals had 16 – 38 years experience of their profession and 6 – 37 of those years in paediatric care.

Data collection

The data collection was performed during 2005 - 2007. Data, field notes from observations, medical records and follow-up interviews, were collected from February - June 2005 in study I, January – May 2006 in study II and January – February 2007 in study III.

Observations

When doing fieldwork as a passive participant observer, it is to experience both the inside, emic, and the outside, etic, perspective. The inside perspective is the view of the participant and the outside perspective belongs to the researcher (Spradley, 1980). Methodologically, it is the duty of the researcher to consider both perspectives just as much (Patton, 2002).

The total observational time for the three studies, including the grand tour (Spradley, 1980), was about 76 hours. The studies took place at the three paediatric outpatient units; the paediatric day care unit, the paediatric neuro-urolgy and bowel disorders unit, PNUT, and the paediatric diabetic clinic. The observer was a passive participant of the situations. Being a passive participant involves to be present but not to interact; it is to find a place from where to observe and record what happens (Spradley, 1980). Participant observations may be most useful for research in paediatric care situations because it can help us to understand how children and their families manage their situation (Carnevale, et al., 2008). Direct observation enables the observer
to understand what happens in an encounter in which the contributories interact (Spradley, 1980). Participant observers have two roles simultaneously: they are the main instrument for collecting the data and they have a lasting analytical role because of the relationship with the data and emergent understanding of the research context (Carnevale, et al., 2008). For an observer, an observation is controlled by the purpose of the study. At first, the observation is descriptive, a very open phase of the method, then it becomes more and more focused and from time to time, it might be selective (Spradley, 1980). This is the way an observation goes, back and forth. In the selective phase, the observer focuses on the differences.

Previous to the first observational study started at the three included units, a descriptive observation, a grand tour, was carried out during a period of two weeks, taking about 36 hours. The grand tour is a description of the space, actor, activities, objects, acts, events, time, goal and feelings (Lofland & Lofland, 1995; Spradley, 1980). In summary, space is the physical places, actor involves the health care professionals, activity is about the related actions and objects are about equipment. Acts is about separate occurrences, events are common procedures and routines, time is the timetable, goal is what the health care professionals are trying to achieve and feelings are what is felt and expressed by the health care professionals. The intention of doing a grand tour was to acquaint the observer with the settings and routines, in addition to getting to know the staff members. Also the fact that the health care professionals came to know the observer and got used to seeing the observer in the setting is important in order to render the subsequent observations as normal as possible. Carnevale et al. (2008) indicate the importance of the participant observer getting to know the gatekeepers and other presumptive participants by being present in the space before the research starts. On the other hand, as the observer was not attached to the units before the study, it is assumed to increase an awareness of the fine distinctions in situations on the part of the observer (Lofland & Lofland, 1995; Spradley, 1980). Spradley (1980) also talks about the observer’s consciousness of what is going on, so called explicit awareness that in daily life would result in overload if it did not change to selective attention.

Each observation started as soon as the health care professional was physically with the minor and/or the parent/guardian and ended when the health care professional or the parent/guardian or the minor separated from each other. During the observation, the observer was placed in the periphery of the paediatric care situation, standing beside or seated on a chair, writing down observational field notes. Immediately after the observation, the
observer recorded a description of the observation, as substantially and completely as possible, using a tape recorder. All data were transcribed as correctly as possible. Field notes bring observation and analysis together and are the most usual way of writing down observations (Spradley, 1980).

In total, there were 138 observations conducted during a total of 41 hours. The observations lasted between one minute and two hours and ten minutes.

**Medical records**

The minors’ medical records were studied after the observations and the text related to the observation was selected for reading. The text related to the aim of the study was written down exactly, word for word and used as data and analyzed, as all is data according to Glaser (1978). There were 35 excerpts: 20, five and ten from the three observational studies (I, II and III) respectively, that were selected and used as data. The rationale for there being fewer excerpts from medical records than there were participants, 35 excerpts in relation to 60 participating minors, is that the data have to be relevant.

**Follow-up interviews**

In the study of the health care professionals, study III, tape recorded follow-up interviews were conducted after the observation had been completed. One of the participants wanted to be interviewed the day after the observation was conducted, because of lack of time. All the follow-up interviews started with the question: “Can you please tell me about the situation I have observed right now?” Follow-up question were. “You said ..., can you please tell me more about that?” Follow-up interviews are viewed as formal interviews and should consist of descriptive questions (Spradley, 1980). There were 15 follow-up interviews conducted and they varied in length from two to 12 minutes. When performing follow-up interviews, the participant’s voice of what is observed is to be heard (Lofland & Lofland, 1995).

No follow-up interviews were conducted in studies I and II, as a result of the participants’ lack of time. The minors were in a hurry to attend their next appointment or examination, or the parents/guardians had limited time. In this regard, the observations were as identical to a normal visit as was possible.
Ethical considerations

Medical ethics has four principles, beneficence, justice, nonmaleficence, and respect for autonomy (Beauchamp & Childress, 2001). The corresponding core values in the UNCRC (United Nations, 1989) are: promotion of the child’s best interests, non-discrimination, survival and optimum development, and to be listened to and taken seriously (Reading, et al., 2009). Alderson (2004) emphasizes ethical research as always respecting the vulnerability of the child. Rights based research involves participation, which includes the children being well informed by others/their caregivers (Alderson, 2004).

Prior to the start of study I, there were eight meetings at the selected paediatric outpatient units; the observer informed the health care professionals about the total the study. The health care professionals at each of the three separate paediatric units gave their informed consent once at the start of the study in which they were involved.

The observer selected who to include in the study and discussed this with the health care professionals until agreement was reached about the suitability of participation. The health care professionals were, in this manner, acting as gatekeepers to the minors. The health care professionals received a written form, detailing how to ask the selected minors and parents/guardians about permission to let the observer inform them about the study. When the minor and the parent/guardian arrived at the relevant unit, the health care professional asked the minor and parent/guardian if they agreed to be informed by the observer about the present study. When they both accepted they were given information by the observer, verbally and in writing. The observer gave the possibility for the minor and parent/guardian to reconsider, by offering to leave the room while they made their decision. These minors and parents/guardians accepted at once. It was compulsory for minors and parents/guardians to sign an informed consent, according to the provisions of the World Medical Association (WMA) Declaration of Helsinki (WMA, 2008). As some of the minors were younger than 15 years, the consent must be viewed as an assent according to the Act concerning the Ethical Review of Research Involving Humans (SFS 2003:460) (Swedish Code of Statutes, 2003). Assent implies that the minor is informed and able to agree or deny (Pieranunzi & Freitas, 1992).

Sometimes it was not appropriate to even ask a minor to participate in the study, depending on their medical, social and/or emotional situation. Alderson (2004) stresses the difficulties in having access in research with minors because of their many gatekeepers, such as parents, guardians and
health care professionals. On the other hand, how to reduce the risks of minors being, more or less, coerced into joining a research project has also been debated (Alderson, 2004) and this cannot be excluded in this thesis, even if it was not obvious to the observer. Alderson (2004) highlights the right to be researched on and, in this thesis; the observational studies are all related to minors 10-17 years, even if the target was the parents/guardians in study II and the health care professionals in study III.

The informed consent contained information about the present study, confidentiality, free will and their right to withdraw from the study at any time without any explanation (Swedish Code of Statutes, 2003; WMA, 2008). Three versions of the form were developed, one for the health care professionals, one for the parents/guardians and one for the minors. This was in order to suit the intended reader, according to the recommendations from the World Health Organization, Research Ethics Review Committee (WHO ERC) (2009). The minors aged up to 15 years were not allowed to give informed consent; instead they gave their written assent to participate. One of the minors was diagnosed as being cognitively impaired and was assessed by the observer as not able to give informed consent, instead giving assent for the observer to be present during the examination. Studies I, II and III were approved, Dnr: 208/04, by the Regional Ethical Review Board (Swedish Code of Statutes, 2003).

Data analysis

Constant comparative analysis

Data from the observations, the medical records and from the follow-up interviews in studies I, II and III, were transcribed by the observer and analysed according to constant comparative analysis (Glaser, 1978; Glaser & Strauss, 1967). Continuously, through the data analysis, memos were written down in a separate note book as soon as they emerged. A memo is an “immediate illustration for an idea” (Glaser & Strauss, 1967, p. 108) and leads to abstraction (Glaser, 1978). Simultaneously, the observer wrote theoretical memos, hypothetical questions to the data, as it is most valuable in the development of a core category (Glaser, 1978).
At first, open coding was carried out, data were read and analysed line-by-line. Open coding is to compare incident to incident, to compare concept to incident and to compare concept to concept (Glaser, 1978). While performing the open coding, the aim of study was in the focus; “What is this data a study of? What category does this incident indicate? What is actually happening in the data?” (Glaser, 1978, p. 57). The codes were sorted into groups of codes with similar substance, substantive codes. The substantive codes were generally labelled with the informants own words. In order to generate categories, the substantive codes were compared to one another. A category is substantive codes with the same meaning and content. Constant comparative analysis concerns conceptual comparison (Glaser, 2001).

Conceptual elaboration is central to theoretical sampling, which is the deductive approach of grounded theory (Glaser, 1998). In accordance with theoretical sampling (Glaser, 1978), the units and the participants were selected to represent variation and differences, in order to achieve saturation. Saturation means that additional data do not result in any further changes to the developed categories (Glaser & Strauss, 1967). The categories were compared to find a common denominator, a core category, which includes every category (Glaser, 1978, Glaser & Strauss, 1967). When the core category has emerged, it is time to carry out the literature review. According to the method constant comparative analysis, literature will be used and analyzed as additional data, so called outside comparison (Glaser, 1978).

Qualitative content analysis

The findings from this qualitative content analysis of the ethical demand (Løgstrup, 1997), were intended to be used in the simultaneous concept analysis (Haase, et al., 2000). The research question posed to the data was: “What is the content of the ethical demand”? The book was read through thoroughly and key examples were extracted and used to the exact formulation of definitions (Mayring, 2004). The findings were two concepts; the mediation and the social norms (table 3).

Mediation is about the space between us, the life scope, where we take care of each other because we are concerned with each other. The mediation consists of: personal empathy, personal integrity, and ethics of understanding of life, trust and interdependence. Personal empathy is about showing each other compassion and could be described as to support, conform and console. Personal integrity is to show each other respect and concerns bodily integrity,
privacy and decision making. Ethics of understanding of life means to have an insight into what is best for the other person and freedom of choice and to listen. Trust is to deliver ourselves to the other person and to be keenly aware of each other and also about the tone in the conversation. Mutuality is to collaborate with each other and is a way to handle the trust between us. Mutuality is also to be interdependent and to participate. In Løgstrup (1997), selflessness was analyzed and interpreted to be a component of mediation, but was excluded since data in the studies I, II and III was collected through observations. “Selflessness can never manifest itself in an action so directly that an outside observer would be able to see it and testify that the action was in fact carried out in obedience to the radical demand” (Løgstrup, 1997, p. 105).

The social norms are about the system we need to fulfil the ethical demand. The social norms include: insight, judgment, shared responsibility and relationship of power. Insight is to have and to share knowledge with each other and to guide and supervise the other person from the other person’s perspective and best in mind. Judgment is to act according to accepted procedures, such as ethics, law, statutes and social rules. Judgment is the way of handling insight and is about protection and an urgent request to show consideration. Shared responsibility means having an obligation to assist the other person and this obligation is based on justified demands. Sharing responsibility involves discussion and information exchange. Relationship of power means to have the possibility of conducting human rights in our mutual relationships. The rights are governed by ethics, law, statutes and social rules. Relationship of power is about equality and interdependence.

### Table 3. Components of the ethical demand

<table>
<thead>
<tr>
<th>The mediation</th>
<th>The social norms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal empathy</td>
<td>Insight</td>
</tr>
<tr>
<td>Personal integrity</td>
<td>Judgment</td>
</tr>
<tr>
<td>Ethics of understanding of life</td>
<td>Shared responsibility</td>
</tr>
<tr>
<td>Trust</td>
<td>Relationship of power</td>
</tr>
<tr>
<td>Interdependence</td>
<td></td>
</tr>
</tbody>
</table>
Simultaneous concept analysis

The simultaneous concept analysis (Haase, et al., 2000) was undertaken to develop a process model of information exchange in paediatric care. The uniqueness of simultaneous concept analysis stems from each concept being developed simultaneously to all other concepts being taken into consideration, and the method explains the individual concepts and the relations between the concepts. Simultaneous concept analysis is a nine step model, each step is described below:

Step 1: The consensus group consisted of the researcher and the supervisors; each individual brings certain expertise to the group, such as nursing care, paediatric care, qualitative research methods and ethical issues.

Step 2: Five concepts were chosen, the three core categories from studies I, II and III; balancing the circumstances, firm handling and sharing and contributing the responsibility, and the two from the content analysis of the ethical demand; the mediation and the social norms.

Step 3: The approach consisted of the constant comparative analysis method (Glaser, 1978) and the qualitative content analysis (Mayring, 2000); concepts are presented in Table 4.

Table 4. Refinement of five concepts and their components to be analyzed

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<th>The mediation</th>
<th>The social norms</th>
<th>Balancing the circumstances</th>
<th>Firm handling sharing and contributing responsibility</th>
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<td>Getting the facts</td>
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Table 4. Refinement of five concepts and their components to be analyzed
Step 4: In order to clarify the concepts, they were discussed in the consensus group. Study I: Balancing the circumstances is how minors interact when receiving paediatric care: balancing what is supportive, what is restraining and what is stabilising. Study II: Firm handling explained how parents/guardians interacted with each other when their minor was in different paediatric care situations and indicates how parents/guardians are close to the minor in diverse ways. Study III: Sharing and contributing responsibility explained how the health care professionals promote the integrity of all the participants, minors and parents/guardians, involved in the paediatric care situation. The mediation is about the space between human beings; where we take care of each other because we are concerned with each other. The social norms are about the system where we need to fulfil the ethical demand. The consensus group discussed until agreement was reached about the antecedents, the critical attributes and the outcomes of all the concepts.

Step 5: A validity matrix was developed where all individual concepts were compared and contrasted with all other concepts (Haase, et al., 2000). This helped to refine definitions and clarify antecedents, critical attributes and outcomes. This specific validity matrix consisted of the five concepts from step 2 and 17 categories and nine components from step 3, in total 26 components.

Step 6: All the individual concepts were re-examined by the consensus group and necessary revisions were made.

Step 7: Now the semantics were taken under consideration as the validity matrices were re-examined. Only necessary changes were made.

Step 8: The process model was developed (Haase, et al., 2000). It should be perceived as an analytic tool.

Step 9: The final step was to present the results in a seminar to colleagues and thereby rework the concepts again. This confirms the ideas of consensus group activity as being the most important, and the process model hereby becomes complete. After the seminar, the process model was modified to some extent.

Validity and trustworthiness

Validity is accuracy of data and, in order to guarantee trustworthiness in grounded theory, the categories have to fit, work, have relevance and be modifiable (Glaser, 1978; Glaser & Strauss, 1967). Fit is when the result is grounded in data and the categories express the pattern in data in an adequate and obvious way, a kind of validity. It is about induction and expresses what
is happening in the empirical situation, as how the participants act in these observations. Work is when the categories explain what is happening in data; they should predict what is going to happen and how these participants are going to act. Work clarifies what is going on in data and is about usefulness. Having relevance is when the focus of the area of research is discussed and of interest and that this result can be used in practise in care situations. Modifiability is openness to development and is when the findings from studies I, II and III can be used in future research and be modified by new results, as in the simultaneous concept analysis. Trustworthiness is guaranteed as the data is systematically collected (Glaser, 1978). In order to convey credibility, the researcher can quote directly from interviews or conversations (Glaser & Strauss, 1967).

Several methods were used, such as observations, documents and interviews. There were three researchers who discussed and analyzed data and, finally, literature was used as data. This can be seen as a triangulation that is systematically built into the method of grounded theory. Triangulation of data is important to improve the probability of the findings to be found credible (Lincoln & Guba, 1985). Trustworthiness was strengthened by using several data sources, such as field notes, medical records and interviews.

Lincoln and Guba (1985) use trustworthiness instead of validity in qualitative research, and formulate it as consisting of: credibility, transferability, conformability and dependability. In the qualitative content analysis of Løgstrup’s ethical demand (1997), credibility is about the concepts being clear and strictly described and that they relate to each other without overlapping. Transferability is that the result can be applied in another context and this is conducted in the simultaneous concept analysis, where the findings from the qualitative content analysis and the categories from studies I, II and III were used. Dependability is about the main thread. Confirmability is that the reader must understand that the components are extracted from the data, as here, Løgstrups ethical demand (1997).

In the simultaneous concept analysis (Haase, et al., 2000), there is a process of constant validation of the concepts during the analysis. Validity is systematically built in the method simultaneous concept analysis and is confirmed through the use of the validity matrix, discussions in the consensus group and in the seminar with colleagues. Transferability is that the advanced outcome intergrade may be applicable in other paediatric care settings than those where the empirical data were collected, the three paediatric care outpatient units.
FINDINGS

Summary of papers I, II, III and IV

Balancing the circumstances (I)

The minors resolved their main concern during information exchange in paediatric care by balancing the circumstances. Balancing the circumstances is the way the minor’s maintained stability in the situation. This stability consisted of the minors taking part, feeling trust, being in touch, sharing mutuality and getting the facts. All this was affected by the family influence, the way the parents/guardians interacted during the visit.

The minors took part by interacting with the health care professionals and also with the parents/guardians. This was facilitated by health care professionals’ attitude and kindness, which encourages the minors to feel trust in the situation. Being in touch and sharing mutuality stabilises the balance in a two-way interaction. Being in touch, when communicating, eases in a verbal manner and mutuality facilitates in an emotional way. Conversation between the minor and health care professionals needs to be based on equality in spite of differences in age and medical knowledge. Trust is a presumption of mutuality and taking part. Getting the facts and family influence are either stabilising or counteractive. Getting the facts is stabilising when sharing information or it can take over, giving the health care professional the advantage in a one-way communication, there being one transmitter, the health care professional, and one receiver, the minor. Family influence is stabilising when regarded as caring and confirmative by the minor or, in contrast, time consuming on behalf of the minor when the family speaks in its own interests.

Minors balance their circumstances when exchanging information in paediatric care and might be able to manage their disease more advantageously the more mature they become. Therefore, the health care professional should focus on the minor either as an individual or as a member
of a family and design information exchange specifically for them; it is not just a matter of age, ability and assessment of decision making competence.

**Firm handling (II)**

Firm handling emerged as how the parents/guardians resolved their main concerns when they exchanged information in their minors’ paediatric care. Firm handling consists of the five inter-related categories: representative advocating, collaborating, aim sharing, supportive resourcing and minor bypassing.

The parents/guardians firm handle the information exchange with the health care professionals because they are dedicated to their minor. While they exchange information, they are representative advocating in their minors best interests. The parents/guardians, minors and health care professionals are collaborating together within the situation and in a responsive approach when aim sharing. When the parents/guardians are supportive resourcing, they are helpful to the minor to the greatest possible extent. Representative advocating and supportive resourcing differs in that supportive resourcing is something that is required by the minor, opposing to representative advocating where the parents/guardians take the place of the minor without asking for permission. Minor bypassing is where the communication is only between the adults, the relation between parents/guardians and the health care professionals, which is an interaction aside of the minor. Sometimes it might occur that the parents/guardians and minors do not cooperate too well with one another. Then it might be possible for the health care professionals to promote them in aim sharing to make the individuals start collaborating. When parents/guardians are mainly representative advocating their minor, then the parents/guardians natural reaction of supportive resourcing must be demanded by the health care professionals. The health care professionals might encourage the minors to participate by asking for their opinion and inviting them into the conversation, to start the collaboration between all the parties.

In this study, firm handling indicates a pattern of how parent/guardians are close to the minor, visualized as being in front of, linked together with, surrounding, under and besides the minor. The results may provide some guiding principles for health care professionals, as the parents/guardians are vulnerable and need to be supported and encouraged into firm handling regarding their minor being in paediatric care. Information exchange is a
subject for parents/guardians to practise by firm handling and this ought to be identifiable, well-known and manageable by health care professionals. Firm handling envisions an opportunity to reinforce parenthood in nursing care and invite minors to informed cooperation, thereby taking part in nursing care from each perspective.

**Sharing and contributing responsibility (III)**

The health care professionals resolved their main concern in the information exchange in paediatric care by sharing and contributing responsibility. This interaction consisted of: interchanging of knowledge, relationship-creating chat, calculated confirming, encouraging actions, dichotomous talking and of situation related effects. When health care professionals share and contribute responsibility, they also promote the integrity of all the participants involved by balancing the caring situation.

Sharing and contributing responsibility involves an interchanging of knowledge, as when the health care professionals communicate in a two-way direction with the minor and/or the parent/guardian and receive an answer. Sometimes the health care professionals try sharing some of the responsibility with the parents/guardians with regard to the minor, to ease their daily function as the family have to live with the minor’s disease. In order to increase the knowledge of the minor and the parent/guardian, the health care professionals interchange medical facts with them. When the health care professionals request the minor and parent/guardian to let them share and contribute to the responsibility for the minor’s care, the health care professionals use relationship-creating chat. This relationship-creating chat is also used to start up the calculated confirming, where the health care professionals in a positive, structured and well aware manner strengthen and back up the minor and the parents/guardians. Calculated confirming can, in a way, be seen as a catalyst and intermediate. Another way of supporting the minor and the parents/guardians in an emotional and psychological way is when health care professionals are encouraging. Encouraging might facilitate the minors and their parents/guardians to share the responsibility. Dichotomous talking is when facts are transmitted from one person to another, and is facilitated by the health care professionals using calculated confirming and the relationship-creating chat between the involved persons. All these above mentioned categories are to be seen in different situation related effects, which are dependent on the circumstance in which they take place. The
outcome of the situation related effects is to be managed by the attendant persons.

As health care professionals give an answer to the minors and the parents/guardians ethical demand to be approached by sharing and contributing the responsibility, they thereby facilitate the process so that all the participants may become partners-in-care.

**Intergrade (IV)**

This study adds a theoretical perspective of information exchange in paediatric care with the ethical demand as a basis. The simultaneous concept analysis resulted in the outcomes: to be interconnected, act according to accepted procedure, completeness, interdependence and social intercourse. These five concepts interrelate to the advanced outcome to intergrade, which emphasizes the significance of promoting the integrity of all involved persons in the information exchange (Figure 3).

Being interconnected concerns being in a relationship and showing empathy and understanding toward the other person, for example when the minor is scared during an examination and needs to be encouraged by the health care professional in order to continue. This relationship is based on trust and a respect of the other person’s beliefs and best interests.

Acting according to accepted procedures is about exercising our rights in society and also about accomplishing our duties, based on justified demands in the society we live in. It is to act in a way to try to understand what is best for the other person. Parents/guardians have their obligations, supported by ethics, laws, statutes and unwritten social rules, in order to care for their minor. Ethics and statutes in paediatric care rule how the health care professional has to act according to accepted procedures while exchanging information.

Completeness involves maintaining the totality of the persons engaged in the information exchange in paediatric care, so they can feel that they have everything that is needed and wanted. Completeness is about fellowship, to be in family cohesion and to work as a team. The family has a duty to share its responsibility with their minor, such as to discuss and inform in a mutual way, at the same time as they encourage their minor. Completeness is also about when health care professionals, parents/guardians and minors share information; at the same time they share, transfer and provide information, all
of them show each other understanding and help and console each other if needed.

Interdependence involves how we rely on each other in mutuality in relations, and to be a nice and supportive partner and be a negotiator in the team, such as when the parents/guardians and health care professionals assist the minors during paediatric care situations. Interdependence includes handling information, such as when the health care professional gives indirect information to the parents/guardians when talking to their minors or vice versa. The information is also handled when all involved provide information to each other.

Social intercourse concerns the interplay between health care professionals, parents/guardians and minors in paediatric care when exchanging information. In social intercourse, the health care professional invites the minor and the parents/guardians into a trustful relationship by being professional and approving. A trustful relation might appear when the health care professionals narrate something about themselves. It could happen that a health care professional told the minors a little about their own grandchildren’s activities and told stories and this is to be seen as relationship creating chat. This could mean that the minors in return dared to talk a little about themselves. It can involve freedom of choice when the health care professionals realize that the minor and the parents/guardians are doing their best and improvement will come later on; everything is as good as it can be at that moment. The power related interaction in social intercourse concerns how health care professionals provide information and facts and exchange knowledge with parents/guardians and minors. The contextual influence of the settings, here the three paediatric outpatient units, support the use of power related communication and the health care professionals are acting according to accepted procedures.

The process model (figure 3) shows the obstacles and enablers of the process. An obstacle to the process of being interconnected is to limit collaboration, as when a minor is not given the opportunity to participate in the information exchange. To ignore is an obstacle in the process of achieving completeness and in the process of achieving interdependence, an example being when the minor is not given the proper attention and thereby does not participate in the paediatric care situation. To control and to replace in discussion are either obstacles or enablers depending on the paediatric care situation. Controlling is an obstacle when the parents/guardians manipulate the paediatric care situation and talk about themselves and their own experiences and problems, but an enabler when the family is in cohesion and
is in solidarity, supporting and respecting each other. Replacing in discussions is an obstacle, such as in representative advocating, where the parents/guardians talk over the head of the minors without involving them. When the parents/guardians and the health care professionals are supportive and help the minor to understand and, in that way, replace the minor in discussions, it is to be assessed as an enabler. Conversation without a relation is an obstacle or enabler to the process of social intercourse depending on the current paediatric care situation. Sometimes information exchange is just about a result of a blood sample or confirmation of a date for the next visit and is then conversation without a relation and must be seen as an enabler. However, it becomes an obstacle when the involved persons are bypassing each other.

To intergrade, changes in stages, it is the approach we have when we interact with each other from the view of what is expected in society. When we are interconnected with each other, we act in the other person’s bests interests. We have got to have understanding in order to find out what the other person’s bests interests consist of and we have also got to respect this attitude, even if it does not agree with our own perspective and beliefs. Whilst we intergrade, we preserve the totality of minors and identify the dependency of parents/guardians and the social interplay on the part of the health care professional in the information exchange in paediatric care. Promoting integrity is an important factor in all critical attributes to the outcomes; being interconnected, acting according to accepted procedure, completeness, interdependence and social intercourse. Intergrade consists of five outcomes in a hierarchical order, where being interconnected is the basis and condition of how to act according to accepted procedure, completeness, interdependence and social intercourse, which in their turn all interact with one another. Being interconnected is the prerequisite to the advanced concept intergrade, which means to join together, step by step with another person through a constant series of interventions.
**Antecedents**

- The mediation
  - To limit collaboration*

- The social norms

- Balancing the circumstances
  - To ignore*

- Firm handling
  - To control**
  - To ignore*
  - Replace in discussion**

- Sharing and contributing
  - Have conversation without a relation**

**Critical attributes**

- To be in relationship
  - To have understanding
  - Promoting integrity

- To have commitments
  - Regulations
  - Promoting integrity

- Teamwork
  - Share information
  - Promoting integrity

- To be a supportive partner
  - Handle information
  - Promoting integrity

- Professional relation
  - Power related interaction
  - Promoting integrity

**Outcomes**

- Being interconnected

- Acting according to accepted procedure

- Completeness

- Interdependence

- Social intercource

* Obstacles
** Obstacles or enablers
Indicates the direction of the process

**Figure 3. Five-concept process model advancing to a new theoretical concept**
DISCUSSION

Discussion of the methods

The need for knowledge in the area of information exchange in paediatric care from all involved parties was the rationale for using grounded theory method. Grounded theory gives conceptual explanations of what is going on in the substantive area (Glaser, 1998), here the three paediatric outpatient units. Another method for conducting this research would have been to use the RIAS (2008), then with a descriptive approach. RIAS (2008) is a method of process analysis applied to audiotapes or videotapes of medical encounters and not from transcripts. The dialogue between patient and physician is coded in categories that relate to each speaker (RIAS, 2008). The interview segments in a typical medical encounter consist of opening, history-taking, physical exam, counseling and closing. Instructions to use RIAS when adaptations need to be made, such as coding pediatric visits, are to consider including "anticipatory guidance" talk. In pediatric care, parents may represent the child and RIAS definitions can also be adapted to these situations, as a triad between the child, the parent and the health care professional. The lack of clear definitions might somehow cause problems in coding (Sandvik, et al., 2002). Comparing the observational studies in this thesis, using grounded theory (Glaser, 1978; Glaser & Strauss, 1967), analysed according to the constant comparative method (Glaser, 1978), RIAS (2008) is a totally antithetical way to collect and analyse data. One of the advantages with grounded theory according to Glaser (1978) is that all is data and thereby the results of a study analysed with RIAS, can be reused and analysed according to constant comparative method. Thereby grounded theory can also be assessed as being modifiable (Glaser, 1978). The disadvantage is that the method is more dedicated to the researcher, not following the method in a correct manner (Glaser, 1978).

The observational method described by Spradley (1980), indicates similarities with grounded theory (Glaser, 1978) as the approach of activity is the general question, “What is going on here?”(Spradley, 1980, p. 73). According to Spradley (1980), the follow-up interviews with descriptive questions are to elicit the participant’s observation of the social situation. Using interviews,
there is always the problem of “conformist respondents”, which is to answer in a way, that the participant finds socially desirable (Holm, 1997). Follow-up interviews were only conducted with the health care professionals in study III. This implies that the findings from studies I and II were not confirmed by the participating minors and/or parents/guardians, but this fact was handled by scrutinizing the medical records and the outside comparison of the literature.

Writing memos (Glaser 1978), is the way of handling the influence of the observer in the observational situation. One minor had been silent during previous visits but talked a little during the observation; another very vulnerable minor made eye contact with the observer all through the observation and all this must indicate the influence on the situation by the observer. The observer was always the last one to enter the room, so as not to interfere with how the participants were placed in the room. In a very few observations the participant talked directly to the observer, who interrupted the observation, answered shortly, and subsequently continued the observation. It is also very important to keep in mind that what is observed is similar to everyone, it is the interpretation that might differ and here there is a cultural aspect to be taken note of. As the observations took place during a period of a little more than two years, February 2005 – February 2007, of course the observer became more and more skilled in performing the observations. At the same time, the observer became more and more just an observer. In the beginning there was a lot of chat with the health care professionals but at the end of the data collection the observer was waiting in the corridor most of the time for the next potential participant, as “another day at the office”. It can be discussed whether theoretical sampling has been used in this study; it is perhaps more appropriate to call the sampling strategic and consecutive, but the intention was to saturate the categories. Glaser (1978) does not support age and gender as relevant until it emerges in the findings that they are important. In this thesis, the age and gender of the minors are used to find the parent/guardian (II) and select the health care professional (III), the sampling might be called theoretical due to that. According to Glaser (1978), it is most important that the researcher is aware of their own preunderstanding of the topic, to have theoretical sensitivity, otherwise the data collection and analysis will become biased. There were three researchers, the observer and two supervisors, who discussed and analysed the findings; the observer wrote memos and theoretical memos, so these realities seem to be noticed and balanced as much as possible. The fact that the observer of these three observational studies is a mother and a paediatric nurse must be taken seriously into consideration due to the theoretical sensitivity. This
circumstance is to be handled methodologically by writing memos (Glaser, 1978).

**Discussion of the findings**

The development of nursing science has gone from nurses being the handmaidens of the physicians to being professionals with independent responsibility (Holm, 1997). Darbyshire (2008) states the importance of paediatric nurses when conducting clinical research, in order to implement the results into clinical practice and thereby provide high quality health care for children and their families. Knowledge of how health care professionals handle the ethical issues in information exchange in paediatric care is not sufficient, and that is what makes this thesis important. Through the simultaneous concept analysis (Haase, et al., 2000) the concept intergrade in information exchange in paediatric care was developed. Intergrade might be illustrated through a young person’s comment: “It is not really about who has the power or intelligence, it’s about the mutual respect within the relationship and how this empowers and allows participation to flow naturally” (Brook, 2005, p.176).

Promoting integrity was a critical attribute in all outcomes in the process model of intergrade: being interconnected, acting according to accepted procedure, completeness, interdependence and social intercourse (figure 3). Integrity is explained as “the quality or state of being complete or undivided” (Merriam – Webster Online Search). Though there were some differentiations in the distinctions of promoting integrity between the outcomes. Promoting integrity in being interconnected implies showing each other respect, using a keen tone in conversation, showing each other acceptance and having consideration. All this together indicates a respect for bodily integrity, which was to be seen at the observations conducted at PNUT (I, II and III), where the health care professionals acted in a way so as to avoid embarrassment over bodily functions and showed respect when carrying out invasive procedures with the minors. This caring attitude is supported in an article by Charles-Edwards and Brotchie (2005), where children’s nurses are educated in how to promote the privacy of children and young people. Martinsen (2006) declares that nurses create frameworks in clinical practice, to avoid patients feeling embarrassed in a situation. If the patient still becomes embarrassed it is because of the nurses have not protected the vulnerability of the patient sufficiently.
In acting according to accepted procedure promoting integrity was more about the duty we have to take care of each other, because of our involvement with one another, as to be aware of each other, our dependency of each other, to respect privacy and human rights and give back power. This approach was visible during the observations (I, II and III) in the paediatric diabetic clinic, where the health care professionals educated and empowered the minors to manage their disease, which have a great impact on the minor’s life. This was consistent with Løgstrup’s (1997) declaration that the ethical demand applies within all relationships between human beings. “It is implicit within all of them, demanding in every instance that the individual care for the other person” (Løgstrup, 1997, p. 105). The importance of this caring parental involvement and support was obvious in a study of 34 adolescents with type 1 diabetes (age 14.7 years of average), because their commitment facilitated the adolescents’ self determination, which resulted in improved metabolic control of their diabetes (Hanna & Guthrie, 2003).

Promoting integrity in the outcome completeness has to do with all persons involved in the caring situation being seen as equal, they rely on each other, they are interdependent and they work together as a team. All this is to be seen in a trustful caring relationship. Løgstrup (1997) formulates the child’s dependency to the adult as; “Although it is in the child’s relation to the adult that the one surrendered to the other in the most far-reaching and fateful sense... A person never has something to do with another person without also having some degree of control over him or her (Løgstrup, 1977, pp. 15-16). This is also in agreement with the literature review, conducted by Mårtenson and Fägerskiöld (2007), which concluded that children’s decision-making competence is in dependent on the surrounding adults’ attitudes, as parents and health care professionals, and not only on their own capacity. Twenty three chronically ill teenagers (13-16 years) verbalised their view of how they preferred to be cared for by health care professionals (Woodgate, 1998). The overall approach was described as careful manoeuvring, as the health care professionals were requested to guide the adolescents in a confident manner and with sensitivity, and these findings might be comparable to the outcome completeness. To limit collaboration is an obstacle to completeness. This was visualized in an interview study by Kelsey et al. (2007) of ten inpatient young people (12-16 years), where they felt included or excluded promptly without any verbal communication.

In the outcome interdependence, promoting integrity deals with a reciprocal interaction and reaction, how to be the deputy and, at the same time, be unselfish and supportive. This is highlighted in the UNCRC (United Nations, 1989) article 3, “… the best interests of the child shall be a primary
consideration...”, and in article 12, “…the right to express those views freely in all matters affecting the child...” where these articles are intertwined with each other. This is a parental challenge, to let the child have the possibility of speaking out, because otherwise the best interest of the child cannot be determined. Parents need information themselves, in order to act in the child’s best’s interest in paediatric care and they also wished to have a good relationship with the health care professionals (Jackson, et al., 2007). The parents needed verbal information in combination with written material, directed to both parent as to child, in order to be supportive.

Finally, in the social intercourse, promoting integrity was about to be in harmony, to be supportive, to provide positive feedback and to show consideration. This might be expressed as “However, no one has the right to make him or herself the master of another person’s individuality or will” (Løgstrup, 1997, p. 27). The parent of child, dying at nine years of age, illustrates the need for health care professionals to create a culture in paediatric care that gives permission to the children and parents to speak out and also to be listened to, in order to give them a voice (Taylor, 2006). This requested and wanted interplay between the family and health professionals might be exemplified as the outcome social intercourse. Holm (1997) explains the ethical reasoning of health care professionals as protective responsibility. This protective responsibility is a special kind of responsibility as it is linked to the vulnerability of the patients.

The verifying part of information exchange (Cegala, et al., 1998), might be where most of intergrade takes place and can be assessed as most important and where agreement is to be achieved between the involved persons. What makes intergrade so important in paediatric care is the knowledge of the influence on the minor of experiences in early childhood as: “Whenever we come into contact with the young, to some extent we contribute to the type of person that they will become” (Chadwick & Tadd, 1992, p. 109). This is brought up to date in a recent report from the Children’s Ombudsman (Barnombudsmannen, 2009), where 742 children, divided into two age groups, (11 and 14 years), participated in a questionnaire study. Ninety five percent of them considered themselves as being respected and taken seriously by the adults at home. But, no more than 47 percent of the children find that the adults showed them respect and that they were taken seriously when visiting a care centre. This finding indicates that changes need to be made in health care to put the UNCRC (1989) into practice and this can be implemented by information exchange applying to the advanced concept intergrade.
CONCLUSIONS

In paediatric care, the minor is the focus of care and the minors’, parents/guardians and health care professionals are the collaborators. There are several rationales why minors should be interconnected in their own care, for example, their need for information exchange, training them to take the view of something concerning them; they feeling fine by narrating their thoughts, needs and wishes and also their human right to verbalise this. The truth can always be told so that a minor can understand; what is required is most careful consideration. There is a big difference between when an adult verbalises “I know what is the best for you” versus “What do you think is the best for you?” The best interests of the minor should always be in the forefront and the mediation in the ethical demand guides how this should be performed. This thesis gives one of the answers as to how this could be resolved: by intergrade. These points of view indicate an approach of collaborating instead of acting in isolation, trying to find out the most suitable solution by negotiation. This attitude is most valuable for a minor, since early positive experiences in paediatric care might influence his/her attitude towards health care for life.

It might now be the right time to re-evaluate the term age-appropriate information, it might be more adequate to find out what information is needed and wanted by the minor in another, more individualized, manner and in what way to do it. Being interconnected involves the health care professional finding out what the minor needs to know by asking and telling and also requesting the minors’ confirmation that all that has been said has also been understood. The parent/guardian needs to be interconnected as well, in order to support their minor at the same time as being informed themselves. All this, when taken into consideration, must influence more or less directly on health care decisions.

Minors, parents/guardians and health care professionals have the human right to participate in a human and child-friendly society. This includes all involved parties being partners-in-care. Paediatric care is not a phenomenon in isolation but is instead responded to by society, governments and care institutions.
IMPLICATIONS

The findings of this study contribute knowledge, which can be used in practice, enabling health care professionals to promote the integrity of the minors and parents/guardians during information exchange in paediatric care. This mutual informing relationship is important among health care professionals in order for them to discuss and implement actions. Intergrade can be applied to nursing science and health care professionals, by understanding the complexity and interrelations between the outcomes and that the unique position of being interconnected could function as a guideline. In order to support the minors and parents/guardians, written and computer based information about human rights ought to be easy to access when visiting a paediatric care unit. This is also valuable to the health care professionals, since it facilitates and emphasizes their information exchange. The information must be suitable and understandable to both the minor and the parent/guardian, and should be provided in their first language. The health care professionals must also be skilled in how to communicate with minors and their parents/guardians about their rights. Minors ought to have the possibility to write notes in a diary, maybe even connected to the medical record, in order to exchange information. To support the parents, the parental education ought to be adapted to the UNCRC. Information exchange applying to the advanced concept intergrade should facilitate the implementation of the UNCRC into daily paediatric care. This should be managed by education of health care professionals. Knowledge how to prepare minors should be highlighted; health care professionals must be able to talk so minors and parents understand what is said and, most important, achieve agreement between the involved persons. Exchanging information is not about judging the minors’ competencies and abilities. There is a need to continue research in this specific area; the method action research might be suitable for improving information exchange in paediatric care. What is needed is further knowledge about how minors and parents/guardians interact when they are in paediatric care. Furthermore, it would also be of interest to find out how health care professionals interact among themselves. Siblings have not been addressed in this thesis but of course when one sibling in the family is ill, the others are also vulnerable and affected by the situation and have needs to be considered and to be part of the information exchange. Finally it would be of great interest to analyze the UNCRC from the viewpoint of the ethical demand.
Informationsutbyte är en väsentlig del i mötet i pediatrisk vård. Fastän barnen måste ses som huvudpersoner i pediatrisk vård, så har det mest forskats i hur de vuxna utbyter information. Därför blev det övergripande syftet dubbelt i denna avhandling. För det första så var syftet att identifiera, beskriva och begreppsliggöra informationsutbytet i pediatriska vårsituationer mellan minderåriga, föräldrar/vårdnadshavare och hälso- och sjukvårdspersonal. För det andra, målet med forskningen var att formulera en teoretisk konstruktion, en teori, av fenomenet informationsutbyte i pediatriska vårdsituationer.


Interaktionen i informationsutbytet hanterades av de minderåriga som ”balanserade omständigheterna” (I), föräldrarnas/vårdnadshavarnas ”handfasta hanterande” (II) och vårdpersonalen som ”delade och fördelade ansvaret” (III). Den kvalitativa innehållsanalysen av Løgstrups etiska krav gav fynden förmedlingen och de sociala normerna. Den samtidiga begreppsanalysen gav slutligen resultatet att gradvis nå samförstånd, vilket innebär att komma överens med varandra, steg för steg, genom en serie av kompromisser. Samtidigt som vi gradvis når samförstånd i pediatrisk vård, så beskyddar vi minderårigas integritet, vi uppmärksammar föräldrarnas/vårdnadshavarnas beroendeställning till oss och genom vårdpersonalens sociala samspel så kommer informationsutbytet att förbättras. Denna avhandling understryker betydelsen av vårdpersonalens förmåga att kommunicera och behovet av utbildning och träning inom området, för att förbättra informationsutbytet med minderåriga och deras föräldrar/vårdnadshavares från ett etiskt perspektiv. Teorin, att gradvis nå samförstånd, förklrar hur detta kan användas och genomföras.
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