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HOSPITALIZED CHILDREN AS SOCIAL ACTORS IN THE ASSESSMENT AND MANAGEMENT OF THEIR PAIN

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Academic dissertation to be presented with the assent of the Faculty of Medicine of the University of Oulu for public defence in Auditorium 12 of Oulu University Hospital, on 20 November 2009, at 12 noon

OULUN YLIOPISTO, OULU 2009
Kortesluoma, Riitta-Liisa, Hospitalized children as social actors in the assessment and management of their pain.  
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Acta Univ. Oul. D 1031, 2009  
Oulu, Finland

Abstract

By acknowledging pain as subjective and only fully perceived by the person in pain, the main aim of this study was to report on the use of qualitative child interviewing and drawings as a research method to elicit hospitalized children’s perceptions and descriptions of their pain experience. Further, the second aim was to contribute to the improvement of pain assessment and management in hospitalized children by approaching the question from the children’s point of view through their words and drawings.

Forty-four children in four paediatric units in a university hospital participated in the study. The data were collected by means of qualitative interviews and thematic drawings. The interview data were analysed using inductive content analysis. The drawings were sorted into categories on the basis of contents, and cognitive competence and emotional disturbances by the Draw-A-Person procedure, and a comparison was made of the data from hospitalized children and healthy control groups.

All the children had experienced pain in different situations while hospitalized. The pain experiences came from four main sources: 1. pain caused by a diagnosed basic illness, 2. pain caused by medical and diagnostic procedures and basic nursing, 3. pain caused by accidents, and 4. inexplicable pain not caused by a particular illness or injury and imaginary pain. In describing their pain, the children emphasized the multidimensional nature of pain and used a number of self-reported pain words to describe physical and psychic pain, as well as evaluative aspects of pain. The children had difficulties in finding positive aspects about pain. The drawings of the hospitalized children frequently depicted medical procedures, whereas the drawings of the healthy controls depicted more family relations. The hospitalized children showed a lower level of cognitive capacity, whereas the healthy control group children revealed a higher level of emotional disturbance. The variety of children’s responses to pain management suggests that children try and can alleviate their pain. The children reported their expectations of professional help and valued the care and attention provided by significant others.

The findings provide research-based knowledge for carrying out research with children, and for healthcare professionals in their assessment and management of children’s pain in a more holistic and child-centred way. Children’s competence to describe their pain supports encouraging their involvement as social actors in pain assessment and management in partnership with health care professionals and significant others. This has to be done with respect for their rights as individuals and the desire to give them a sense of ownership of what happens during hospitalization.

Keywords: child, Draw-A-Person procedure, pain experience, qualitative interview, thematic drawing
To Sofía and Samuel
Acknowledgements

This study was carried out at the Department of Paediatrics, University of Oulu, Finland. I am grateful to Professor Mikko Hallman, MD, Head of the Department, who gave me the opportunity to conduct my study at the department and gave me important practical advice. In the course of this research project I have grown as a scientist and as a human being with the support of many people. They have all made a generous contribution to the final version of my thesis. My views on and attitude to child pain have both changed and deepened during the study. The outcome would not have been the same without all the experiences I have had over the years. There are more people deserving thanks than can be acknowledged here.

First and foremost I would like to thank the hospitalized children who participated in this study for sharing their experiences and making this work possible. Their rich contributions are the foundation of the analysis presented here and will hopefully lead to improvements for the assessment and management of pain experienced by hospitalized children. I also wish to express my gratitude to the nurses at the Department of Paediatrics and Adolescence of Oulu University Hospital, who helped me in such a kind and friendly manner. My thanks also go to the control group children from a daycare centre and an elementary school, as well as to their group leaders and teachers for their assistance.

I owe my deepest gratitude to my teacher and co-author, Professor emerita Maija Hentinen, PhD. She introduced me to the complicated world of child pain research when I had just started my nursing studies at the University of Oulu. I deeply respect her for her vision in seeing the future child researcher in me, as well as for her efforts in guiding me in my research career.

I wish to express my special thanks to my main supervisor and co-author Adjunct Professor Merja Nikkonen, PhD. She has been an inspiring mentor, providing valuable advice in each phase of the research process. She has been my teacher and supervisor for many years. I appreciate the independence that she has given to me during this research project and the support and advice she has provided whenever I needed it. It has been a privilege to work with her. It is not easy to find as benevolent a scientist and supervisor as Merja is. I am deeply grateful for her constant friendship and care for me during these years. I also wish to express my sincere gratitude to my other supervisor and co-author Professor Willy Serlo, MD, for his expert knowledge and stimulating and positive attitude toward my research.

An important person for the completion of this thesis has been my co-author Professor Raija-Leena Punamäki, PhD. She introduced me to the analysis and interpretation of drawings. I greatly respect her expertise in this method and in scientific writing. I sincerely thank her for her guidance and support throughout the
study and particularly for her critical comments on earlier drafts. She has been extremely helpful and supportive.

It is my pleasure to thank the official reviewers of this thesis Professor Bernadette Carter, PhD, and Professor Eija Paavilainen, PhD, for their encouraging and constructive comments, which were of great help in the final revision of this thesis.

I warmly thank Tero Suutari for his help with the tables and figures of this thesis. I also express my appreciation to Hilary Keller for revising the English language of the original papers and the final manuscript, and my colleague Bärbel Fink for her friendly assistance. I thank my supervising manager, Professor Anna-Maija Ylimaula, Head of Learning and Research Services, University of Oulu, for her support and encouragement.

I am very fortunate to have a few good friends both near and far away, including those with hoofs and hairy ears. They have added color to my days and assured that I have a life also outside research. My friends, thank you for those memorable moments we have shared. In particular, I wish to thank Wilma and Piet for their sincere friendship. “Life is beautiful.”

My late mother, Ksenia Vuolijoki, deserves my great admiration and thanks for always having faith in me. I also want to express my sincere thanks to my dear sister Marja-Leena. She has played an important role in my life.

My special thanks go to my family. I am grateful to my daughter Hanna-Leena for her help and support in everyday life and her sympathetic presence during all the turns of these years. I am also grateful to my son Jani and his wife Heini, for all the precious moments we have shared during the past years. My grandchildren Sofia and Samuel have offered me enjoyable moments that reminded me of the meaning of life. They have taught me more than I have ever learned before. The time spent with them has been like rays of sunshine.

Finally, I want to express my greatest love and thanks to Pentti, my husband. This work would not have been realized without his support, unfailing patience, and unselfish attitude. He has been my personal helpdesk. He has always believed in me, even more than I myself. I am everything I am today because he loved me and believed in me.

This work was supported financially by the Alma and K.A. Snellman Foundation, Oulu, Finland; the Finnish Concordia Fund, Helsinki, Finland; the Competitive Research Funding of Oulu University Hospital (EVO-funding), Oulu, Finland and the Oulu University Scholarship Foundation, Oulu, Finland. My thanks go to these organizations for their valuable support.

Kivelä Farm House, November 2009

Riitta-Liisa Kortesluoma
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1 Introduction

I took an interest in the phenomenon of pain in hospitalized children while working as a Clinical Laboratory Scientist in a university hospital. One of my tasks was to draw blood samples from children of different ages. My daily observations of children’s very different behaviour when having to deal with pain caused me to reflect on the pain experienced by hospitalized children and its effects on their lives. My first study dealing with pain in children (Kortesluoma 1991) focused on the assessment and interventions used by nurses, during venous punctures to draw blood from 6-year-olds. It showed that nurses often assess pain from an adult’s point of view and do not understand the child’s viewpoint. None of the nurses participating in the study had asked the children to give a subjective assessment of their pain and fear, although the children in question were able to communicate verbally. Nurses did not act systematically and logically, instead they acted apparently randomly when helping children during pain- and distress-provoking procedures (Kortesluoma & Aavarinne 1992).

It is important to obtain knowledge of child pain from the various points of view. In my research for my Licentiate (Kortesluoma 1999) in Health Sciences I examined the pain phenomenon from the point of view of children. Taking this viewpoint into consideration is one way of making nursing care more client/patient centred. Consequently, the subject and the obtained knowledge is not only useful in the field of nursing, but for any occupational groups working with children.

All persons with pain deserve prompt recognition and treatment. Pain should be routinely monitored, assessed, reassessed and documented in order to facilitate pain management and communication between health care professionals (Gordon et al. 2005, Herr et al. 2006) and children. This is imperative when dealing with ill young children because their views may not be heard due to illness, and because they are vulnerable due to their level of cognitive development, limited communication abilities (Knox & Burkhart 2007), hospitalization and their abilities to use coping strategies or professional attitudes.

Studies of children have a long history, but the literature on young children is for the most part filled with studies on, rather than with, children which take little account of what is regarded as significant and meaningful by children themselves (Neill 2005). In both clinical and research practice, children typically have been treated as passive objects of the study (Barker & Weller 2003). The focus has been on what happens to children and the processes they undergo rather than what they have to say (Allred 1998, Christenson & James 2000, Carter 2004). Traditionally,
children’s views have been sought from proxies – such as parents, teachers, health care professionals – rather than seeking the views of children themselves (Forner et al. 2005, Alderson et al. 2006, Coyne 2006). The patient’s self report of pain is the single most reliable indicator of pain (Beyer et al. 1990, Jacob & Puntillo 1999, Simons & Roberson 2002), adults and parents cannot be assumed to give a valid outlook of the child’s experiences (Miller 2000, Murray 2000). Due to the subjective nature of the pain experience, children’s self-reports should be the most reliable source of the data used in the assessment and management of their pain. However, researchers have relied almost exclusively on adults when collecting data concerning children’s thoughts, feelings and experiences (Kortesluoma et al. 2003) and children’s views are seldom published in health literature (Carter 2002b, Alderson et al. 2006).

Pelander et al. (2006) reviewed Finnish academic theses (n=2126) in the field of nursing science between the years 1979-2004. Only 68 (3%) of them (master’s, licentiate’s and doctoral dissertations) used children as informants. In ten of these studies the children were under 12, and out of these ten only three studies focused on participants under 7 years of age. A similar scenario is found on international level. Quite a small proportion of nursing research has been conducted using children as informants (Beal & Benz 1993, Kiernan et al. 2005).

A minimal amount of research has focused on young children’s perceptions of pain, perspectives of their pain experiences and perceptions of practices relieving pain. The reason for the small amount of studies from the children’s own point of view might be the methodological problems related to researching children, such as a lack of adequate methods and assessment tools (Coyne 1998, Murray 2000, Marshman & Hall 2008). The key barrier is a widespread belief that it is very difficult to get information from young children who have a limited vocabulary and level of cognition. Children have not been trusted as informants because of the assumption that children are not able to understand and describe their lives and experiences on the grounds of their immaturity (Coyne 1998, Lowden 2002). Moreover, further explanations for this might be ethical reasons as the child’s ability to give informed consent (assent) (Coyne 1998, Lindeke et al. 2000, Rossi et al. 2003, Heath et al. 2007) and the difficulties of establishing meaningful interaction with children (Medforth 1995, Kipnis 2003, Kortesluoma & Nikkonen 2004).

The situation is changing because researchers as well as health care professionals have increasingly recognized the value of obtaining children’s own perspectives on their lives and health (Carter 2002b, Kortesluoma et al. 2003, Lightfoot & Sloper 2003, Oldfield & Fowler 2004, Rice & Broome 2004, Cremeens et
al. 2006). However, we still know little about the views and experiences of children especially those hospitalized and with experience of pain. Children could inform about more effective approaches to pain management in hospital settings. Eliciting children’s views and documenting children’s experiences of pain are essential in advancing the knowledge and management of childhood pain, providing services responsive to their needs and relieving the associated burden for children. In practice, the needs of the child should be noticed and respected as well as those of the adult.

Sharing children’s experiences of pain requires health care professionals to be active in interaction with children (Carter 2004, Shin & White-Traut 2005). Huber and Cladinin (2002) contend that the sharing of children’s pain stories allows healthcare professionals to relate to children and their experiences and engage with children in a meaningful way. Being able to relate means creating a moral obligation to care for children’s pain and doing so in a way that is the opposite to being superficial and routine. Being able to relate enhances one’s own will to better understand each child’s pain.

In the literature, I could not find any studies conducted with children as young as in this study (four to eleven years), using qualitative child interviewing with open ended questions and children’s drawings as the research data and focusing on a general paediatric population. There are some Finnish studies concentrated on specific patient groups such as post operative children (Pölkki et al. 2003, Pölkki et al. 2008) and preterm or neonatal infants (Axelin et al. 2006, Axelin et al. 2009). Drawings are a well recognized projective method to receive developmentally salient information about children’s experiences. Only one research study (Pelander et al. 2007) reports using children’s drawings as research data in nursing science in Finland, although drawing as a projective method suits young children well (Murray 2000, Ryan-Wenger 2001).

From an international point of view, there is an increasing interest in the child perspective on pain (e.g. Cummings et al. 1996, Woodgate & Kristjanson 1996, Pölkki et al. 2003, Idvall et al. 2005, Huth et al. 2004, He et al. 2007). A few studies have attempted to find simultaneous representations for different states of pain (e.g. Perquin et al. 2000) and very few studies have dealt with the representation of pain among randomly chosen hospitalized children (e.g. Johnston et al. 1992, Cummings et al. 1996). The data collected in most of the studies in Finland and abroad conducted with children are based on behavioral observation, surveys, semi structured interviews, forced choice questions, questionnaires or un-blinded exper-
iments. However, Wilkinson (1988) states that child studies based on questionnaires will reveal minimal information in relation to the children’s total views.

In this research my aim is to challenge health care professionals to listen to what children tell us about their pain and to value their pragmatic truth. The aim of this study was to investigate and describe the personal views of a general paediatric population regarding their experiences of pain during hospitalization using qualitative child interview and thematic drawing as methods of data collection to contribute to the continuing development of high quality, child-centred care. Effective pain management requires a state-of-the-art knowledge of the pain experience as produced by the children themselves.

This research consists of five original publications and a summary. The original articles identify and describe methods in qualitative child interviewing (Paper I), the sources and causes of their pain experiences in 4- to 11 year-old hospitalized children (Paper II), 4- to 11 year-old hospitalized children’s pain descriptions and views of the purpose of pain (Paper III), describe and understand 5–11 year-old children’s pain through their pain drawings (Paper IV) and identify and describe the pain alleviation methods young children use themselves and their expectations of other people’s help, when managing their pain during hospitalization (Paper V).
2 **Theoretical approach to the study**

There is some kind of explicit or implicit assumption of human reality in every research methodology. By the theoretical approach to this study I mean the pre-judgements which contribute to my orientation of the phenomenon studied and the children who collaborated with me in the research project. In this context I concentrate on the philosophy of childhood and the child’s point of view. Moreover, I define the phenomenon of pain and pain experience in the context of paediatrics. Because language forms the most important contents of socialisation and is its paramount instrument (Berger & Luckman 1991: 153), I discuss here the language in the context of pain experience and describe children’s drawings from the developmental point of view. In addition I consider an adult’s ability to understand children and their experiences. I clarify these issues because the way in which I conceive childhood shaped my research and the assumptions and concerns I brought to the research process shaped the methods I employed.

2.1 **The philosophy of childhood and child’s point of view**

In order to understand children’s experiences of pain, it is important to consider the philosophical aspects of childhood. Adults’ conceptions of childhood, attitudes toward children, knowledge and theories of developmental issues all influence the way how children’s pain is understood, intervened and studied. Further, children's rights, notions concerning the status and significance of the child affect on hearing children’s voice in health care.

Considerations on children and childhood are mediated by culture and history as well as the definitions of the human and life. The discovery that childhood has meant and may mean different things to children and adults in different cultures and historical periods both enriches and complicates the philosophy of childhood. (Kennedy 2000.) Primarily, childhood is a relational term, because of its relationship of difference with adulthood (Jenks 1982). According to Greig and Taylor (1999) children are very special people. This means that they are different from adults, who control and describe the world as we know it. Kennedy (2000) came to the conclusion that childhood is constructed by adults.

Developmental theories provide parameters to better understand the human condition and to show what is generally expected at different stages in life. While different human developmental theories are conceptualized in various ways, it is

Developmental psychology presents a universal developmental perspective on childhood, drawing extensively on the theories of Piaget (James 2001). This perspective influenced thinking in both psychology and sociology and is based on ideas of natural growth (Kirk 2007). When studying children’s pain problems from the point of view of cognitive development, Piaget’s genetic epistemology (Piaget 1965) has been used as the theoretical perspective during the past two decades. One of the most salient constructs, based on Piaget’s theory, is that children of all ages reason and comprehend things according to more or less internally consistent principles. Generally these principles are extremely unlikely to be explicit to themselves or others. A child builds up his/her knowledge through elements called schemata. A developing child builds up and connects these schemata continually when trying to construct a cognitive map out of his/her world. (Bush & Harkins 1991.)

Moreover, in studies focusing on children’s understanding of illnesses, the cognitive development of children is understood to proceed through stages as described by Piaget (1973) (e.g. Burbach & Peterson 1986, Thompson & Varni 1986). According to Piaget, children’s thoughts, perceptions, and reasoning usually differ qualitatively from those of adults. The differences do not stem from a misunderstanding rather they reflect children’s own interpretations of events. Piaget’s (1973) theory suggests that these interpretations proceed through a set of stages from infancy to adulthood and that there is an end point or goal. These stages describe the approximate stages of life, when a child moves from one stage of development to another. These stages are only suggestive, and with this general exposition it is not possible to predict anything in relation to children’s understandings of pain. Of course, a child’s age is only an approximation of the developmental level, and within any age group there can be considerable variation with respect to the developmental level.

Modern cognitive development has largely moved away from the Piagetian theories of stages even though, it is generally acknowledged, that children’s understanding of illness differs with age (Neul et al. 2003, Forsner et al. 2005, Myant & Williams 2005). For example, in the research of Boruchovitch & Mednick (1997) it is indicated that with advancing age (4–16) children are able to give multiple definitions of health and to discuss more abstract concepts. The finding is compatible with the Piagetian views of development in which children gain increased ability to ‘decenter’ and view things from various perspectives. However, some
research shows that an understanding of illness not only relates to age, but also to previous experiences and the severity of the illness (e.g. Crisp et al. 1996, McQuaid et al. 2003). Even though Piaget did not focus on the pain phenomenon, his theory corroborates many perceptions of knowledge related to pain in children (e.g. Gaffney & Dunne 1986). One could hypothesize that children’s understanding of pain might progress with age and experience.

Matthews (1980) provides a powerful antidote to the widespread tendency in research to underestimate children's mental ability and patronize their natural curiosity. As Matthews shows child psychologists, even those as insightful as Piaget have failed to grasp the subtlety of children’s philosophical frame of mind. Matthews’ examples reveal children’s ability to reason about these problems in a way that must be taken seriously by anyone who wants to understand how children think.

In the literature, several definitions show children as immature, growing and developing towards adulthood (Marin 1988). The construct of children as becoming humans, rather than as human beings, has exacerbated the objectification of children in research, health care and society (Driessnack 2006). On the other hand, the concept of ‘child’ may also mean something other than a biologically young human being. It can also be thought of as representative of some intrinsic human quality independent of biological age. This would mean that childhood does not end when adulthood begins, but that adulthood comes as an addition to childhood (Hellsten 1992: 13).

The development of children’s rights led to a different way of thinking about children and childhood based on interactionism and social constructionism in the late 1980s and reframed the social status and position of children (James & Prout 1997, James 2001). According to this perspective, childhood is socially constructed and emphasises the social, cultural and historical variability of childhood (James & Prout 1997). These sociological approaches to childhood suggest focusing upon children’s lives, perceptions and activities rather than viewing children as future adults. This shifts the idea of a child as “becoming an adult” to “the being child” (Qvortrup 1994). Therefore, childhood can also be seen as a conceptually autonomous arena. It conceptualises childhood as different, not in the sense of being a stage towards adulthood, but as another culture, a world relatively autonomous from the adult world. This perspective views children as possessing different experiences, knowledge and competencies to adults, and as being competent social actors in their own right. Thus, children are actively involved in responding to and
shaping their social worlds, not merely a prism through which to examine adulthood. (Coad & Lewis 2004, Hutchby 2005.)

From this perspective children are constructed as active participants in research (Hill 1997, Kirk 2007). The research also emphasises that it is inappropriate to use adults as proxies for children when seeking children’s experiences and views (Mahon et al. 1996). According to Dixon-Woods et al. (1999) and Kirk (2007) adult proxies cannot give valid accounts of children’s social worlds, because adults and children have different views and they experience events and situations differently. Instead, researchers ought to recognise and reject the prevailing underlying presumption of adulthood as conferring competency as a research participant. This supports James et al.’s (1998) model of the ‘social child’, which proposes child and adult research respondents as comparable, although children possess different competencies and are skilled in different methods of communication. Nonetheless, they are competent and confident in those methods and researchers must avail themselves of those competencies.

2.2 The phenomenon of pain and pain experience in paediatrics from different perspectives

The word “pain” is used in many contexts, where it is not necessarily connected to physical sensation. Looking through the literature, it can be noted that the definition varies with the perspective of the person using the term. Until the 1960s definitions of pain provided only the physiological elements and defined pain from the tissue level, not the human level. A scientific, comprehensive, worldwide respected and frequently quoted definition of pain is proposed by the International Association of the Study of Pain (IASP), and as Carter (2004) states, it constitutes a cornerstone in professional and academic thinking about pain. IASP (1979) defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore an emotional experience.” This definition defines the various types of pain experienced by adults. However, it also highlights some of the problems associated with the recognition of paediatric pain. The emotional response may be quantitatively or qualitatively different in younger infants. Moreover, this simple definition leaves little room for the affective dimension of this ubiquitous experience of pain. According
to Carter (2004), the definition is at the same time both all-inclusive and vapid. It admits the emotional dimension of pain, but it lacks everything of the individual emotional experience. Unrelieved pain changes a person’s worldview and has major implications for persons experiencing pain but the IASP definition expresses neither of these aspects. It includes the subjective dimension of pain but no stance is taken whether this applies emotionally or physically.

McCaffery (1979) defined pain somewhat differently, from the point of view of nursing, as being what the person in pain says it is. According to the definition, pain exists when the person experiencing pain says it exists. The strength of the definition lies in its emphasis on the subjectivity of pain and the uniqueness of the pain experience. McCaffery's contribution is often recognized as providing a clinically relevant, simple definition. More importantly, the definition challenged the field of pain management. McCaffery's admonition that "pain is what the person says it is …" was also a different voice. This nursing voice spoke of pain as personal, as individual, and of the patient as an expert. McCaffery laid a foundation for respect for people in pain. The definition is widely accepted although it has its limitations (McGrath & Graig 1989, Algren & Algren 1994, Anand & Craig 1996, Coffman et al. 1997, Kokki 2001). It seems that an all-embracing definition of pain, that suits children, is still out there waiting to be found. Clearly, the definitions of pain are not permanent. The experience of pain is affected by a group of variables and contextual factors (e.g. Hayward 1975, Stevens et al. 1987, Bournaki 1997, Goodenough et al. 1997, Loeser & Melzack 1999, Shields et al. 2005) and even persons affected by the same kind of stimulus react differently.

Perception and interpretation are two distinct aspects of pain, representing two different mental functions. Many factors influence pain perception, including age, gender, individual history and culture. Suffering is the result of how pain is interpreted. Moreover, suffering can both ensue from pain and be a source of it. (King & McCool 2004.) Our interpretation and perception of pain will develop with experience (Anand & Craig 1996).

Pain is a holistic phenomenon affecting a person's body, mood, social participation, and spirit (Meinhart & McCaffery 1983). Physiological and behavioural studies have shown that pain response is individual and that social learning and experience have a role in pain, as well as the effects of genetic differences, anxiety, or expectation (Loeser & Melzack 1999, Young 2005). Therefore, the meaning given to an individual pain experience significantly affects the pain expression and coping with pain and demands a unique response.
2.2.1 Pain experience and language

Pain experience belongs to everyday life and the experience can be shared with others through language. The use of language is a part of the pain experience. Language legitimizes the experience of pain. (Waddie 1996.) According to Wittgenstein (1967), pain is a part of public, communicative language. Therefore, pain exists only in a common form, and there is no private pain expression. Wittgenstein proposes that private pain exists only when an individual experiences pain, and another may only guess it. He suggests that there 'must be some feature of our pain which advises us of the whereabouts of the pain in the body' (Wittgenstein 1967: 185). If the pain is regarded as private and public, its public manifestation occurs when pain is expressed (through language). The pain unexpressed to others is private and restricted to an individual’s perceptions of the physiological responses of pain. (Waddie 1996.)

Wittgenstein (1967: 185) considers pain as ‘something special and indefinable. But it must be possible to teach the use of the words.’ This is how pain expression inextricably relates to language. Pain expression becomes part of public language because words are taught to define the meanings of stimuli. According to Giddens (1989), language is the most straight or sophisticated human characteristic, and transition from private to public pain goes by verbal communication. Furthermore, according to Wittgenstein (1967) pain exists only when expressed. Therefore pain is not an individual in pain or an individual sensation. Instead, pain is seen as an expressed pain behaviour and accompanying language. In clinical nursing, this may mean that many may experience pain which is not expressed and is therefore not relieved. The work of Wittgenstein requires health care professionals to accept the challenge of his theories in relation to language as a part of pain experiences and pain expression. They question the ignoring of silence and assumption that it indicates an absence of pain. In 1994, the IASP broadened the definition of pain and included among other things the following additional point: “The inability to communicate verbally does not negate the possibility that an individual is experiencing pain and is in need of appropriate pain relieving treatment.”

The relationships between feeling pain and reporting pain are highly context-dependent. A child’s way of speaking about her/his pain, that is a child’s language of pain, is affected by the age (neurophysiological development), the stage of the child’s psychological growth and development (cognitive and emotional development) as well as the experiential development of the child, defined by the
child’s previous experiences of pain and by the meaning of this kind of experience to the child. Also, the significance of family and culture are relevant factors to the experience of pain. (Stevens et al. 1987.)

2.2.2 The cognitive and drawing development of children

In the next sections I will describe children’s cognitive development in relation to the language of a child according to the theory of Piaget (1972). I illuminate factors behind children’s drawings and introduce the typical developmental characteristics of children in art production as established by Lowenfeld (1947). Moreover, I focus on children’s memory development as well as an adult’s chances of catching a child’s experiences.

The cognitive development and language of a child

According to Piaget (1972), the cognitive development of a child consists of four stages, each of which has a certain schema or model: at the sensorimotor stage (from birth to 24 months) a child’s actions are reflective; a feature of the preoperational stage (2–7 years) is a child’s egocentric thinking; at the stage of concrete operations (7–11 years) a child is able to accommodate another’s point of view and at the stage of formal operations (11–15 years) a child is capable of abstract, multi-faceted thinking.

Because, the participants in my research study are children, aged from 4 to 11 (explanation on page 48) I describe the characteristics of cognitive development of children at the preoperational and concrete operational stages as well as their perceptions and understanding of pain.

Children (of 2–4 years of age) at the beginning of the preoperational stage think in a very concrete and self-centred way. The child understands best those things that she/he is able to see or touch. At the preoperational stage a child creates both figurative and verbal images, which are related to her/his own experiences. She/he does not realize facts, and instead believes things to be as she/he wishes or perceives them to be. (Piaget 1988.) A child’s thinking is dominated by sensations and children often believe that inanimate items have feelings (animism). For this reason, for example, a child may say that a needle for taking blood hates her/him. Children may also focus on a characteristic or a feature of an item and proceed in their thinking from one certain detail to another. A pre-schooler sees two simultaneous events in a cause-effect relationship to each other. These characteristics, at
this age, are known as concentration, transductive thinking and phenomenism (the cause of an illness is an external concrete phenomenon which may co-occur with the illness but is spatially or/and temporally remote). (Smith 1976, Bibace & Walsh 1980, Sheredy 1984, Lutz 1986.)

At the age of four, after speaking for a couple of years, a child begins to master the pivotal structure of language. A child expresses her/himself by all accessible means: eye, motion, expression and by sounds varying in both strength and intonation (Tornéus 1991). A child’s talk is situational talk. It refers to here and now situations, issues and events, which are directly present. At this stage of development, a child’s meanings for words may be either broader or more limited than adult language. (Meinhart & McCaffery 1983, Lutz 1986, Leiwo 1989.) A child’s language development prepares the way for questioning. However, often she/he is so busy that she/he does not have time to listen to the answer. This is followed by a total misunderstanding of the message. At this age, a child usually answers questions accurately, but in a one-sided way. Moreover, the child repeats the same words and sentences. (Leiwo 1989.)

In infancy (2–7 years) a child is egocentric and has difficulties in separating fact and fable. The child can not realize that her/his experience of an event may be different from that of another. Even though the child’s verbal skills have developed considerably, they usually are still too limited in order to enable conversation about thoughts and feelings. At the preoperational stage the child has only limited ability for abstract thinking. Even if a child’s verbal competence improves, her/his reasoning remains empirical and is in connection with direct experiences. (Ross & Ross 1988.)

At the stage of concrete operations (7–12 years), the most important change involves separating self from others (Piaget 1973). A child begins to separate the internal from the external. At this stage a child explains words according to the literal, concrete meaning of them, finds opposites and tries to get rid of egocentric reasoning. Some of the children at this stage of their cognitive development are able to understand the connection between cause and effect. They may remember their experience for years. At the stage of concrete operations, a child may imagine things without seeing them, but her/his reasoning is still linked to perception. Along with cognitive development, children’s capacities to adopt an external and speculative attitude towards phenomena increase (Tornéus 1991). They have only a limited ability to understand and define abstract concepts, as well as discuss them (Piaget 1972). According to Blos (1978), the reasoning of school children is a combination of reality and fantasy. They use imagination in order to add their
knowledge. Under duress, children may regress in their development and lose some cognitive capacities typical of the age in question (Blos 1978).

The nature of a child’s direct subjective experience is reminiscent of that of an adult because a child connects various things together more freely. Lehtovaara (1992: 73) states that a child must be seen as an individual giving sense to his own life. Every child has their very own way to examining and shaping reality. This development continues throughout their whole life. Korkiakangas (1993) concludes that the prevailing theories of cognitive development indicate that the child’s understanding of the world is qualitatively different from that of an adult; however generally a child finally ends up understanding the world as an adult does.

The meaning and development of children’s drawing

Drawing comes naturally to most children as part of their “being” and the most obvious reason children draw is for the sheer pleasure of it. Drawing is also a natural play activity for children stimulating their development and creativity (Ryan-Wenger 1998, Barraza 1999). Drawing has a special status during childhood because through pictures a child is able to express her/himself when her/his verbal and literacy skills are still developing. It may moderate the retrieval process and help children convey their thoughts and feelings and allow them a better opportunity to share their voice with a means of communication other than using words. (Bricher 1999, Clements et al. 2001, Salmon 2001, Veltman & Browne 2002.)

Drawing is a form of visual language (Hawkins 2002). Gallas (1994: 15) claims that children's personal narratives, formed in an attempt to order and explain the world from all aspects of their experience, ‘are often part of the silent language that embodies thinking’. She does not confine the communication to the spoken or written word, but includes the stories children tell from early childhood ‘in their drawings and paintings’.

Developmental changes in children’s drawing

Drawings can provide another cue to the child's developmental level. As with any other skill or ability, the drawing skill follows universal developmental sequences children tend to go through as they develop. (Kellogg 1969, Piaget 1969, DiLeo 1970, Lowenfeld & Brittain 1987, Carrol & Ryan-Wenger 1999, Picard & Durand 2005.) The most frequent description of the typical developmental characteristics
of children in art production is by Victor Lowenfeld (1947). This information is routinely used to assess and understand the developmental issues of clients in art therapy practice. Many issues have been identified which warrant a re-assessment of these long-accepted measures. Some of these issues include cultural factors, societal changes, and out-dated research methods. However, a review of these issues may or may not significantly influence or change what Lowenfeld (1947) established. According to DiLeo (1983) it is essential to understand drawing development in children; as otherwise, inappropriate interpretations may result.

In the Sensorimotor Stage, at the age of 1½ to 2 years old, children scribble continuous lines and single shapes not resembling any recognizable subject. Children draw shapes consisting of continuous lines such as swirls, loops and, on the other hand, they draw shapes which originate from separate frequently drawn lines (Golomb 1981, Kellogg 1969). (See Figure 1, on page 28) At the end of the Scribbling Stage (ages 18 months to 3 years) children begin to name their drawings: e.g. big witch, grandmother’s horses, etc. The phenomenon indicates that the child detects and is interested in events around him but she/he cannot draw them yet (Kellogg 1969). At the age of two to three years, symbolic function is strongly present in children’s play, imagination and imitation. The transition can also be seen in the drawings. Their scribbles consist of quickly drawn smooth lines and more intentionally drawn angular lines (Adi-Japha et al. 1998).

At the ages of 3 to 4, at the Pre-Schematic Stage, graphic communication begins; shapes tend to be geometric and children draw intentional combinations of circles, squares and crosses. According to Mortensen (1991) a developmental shift occurs at this stage when children begin to name their pictures before drawing them. This indicates that they have a concept in mind which needs to be transferred into a drawing. There is a relationship between the child’s intention and product. However, at the Pre-Schematic Stage children’s pictures are only a bit suggestive of their model (Piaget & Inhelder 1977: 65). A child views every object and thing like her/himself. In children’s drawings, this attitude appears as value statements and a child draws things or creatures which are valuable, important and frightening to her/him as excessively large or otherwise distinguishable. (Kowalski 1973: 78–80.)

Drawing serves as an indicator of general development but it is also an important factor in facilitating development. The change can be seen in children’s drawings in which simple and concrete schemata become richer and more precise. The child begins to combine shapes that he learned and practised earlier. At first s/he combines two shapes, often a circle and a vertical or horizontal line. (See Figure 2,
This creation is called a Mandala, the first human figure drawing (HFD), which is a circle with a cross through the middle (Goodnow 1977). The “mandaloid man” also called the “tadpole man” typically consists of a circle for the head with two smaller circles for eyes, another circle for the mouth, and two vertical lines from the head for legs (Lowenfeld & Edwards 2000, Ryan-Wenger 2001). Arms are generally omitted in early drawings.

At the end of the Pre-Shematic Stage a child is able to draw clothes, hair and other details to a human figure (Alter-Muri 2002). A child uses her/his own favourite colours of the colours open to her in order to describe things and emotions which are important to her/him (Lowenfeld & Brittain 1987: 225–226).

By the age of 6, at the Schematic Stage of drawing, the child has a definite way of portraying an object. Regularity typifies human figure drawings, this is to say, that children draw the body parts downwards: i.e. first the head, then the body, hands and legs, after that they add the eyes, mouth and other parts of the face and the details of body parts (Golomb & Farmer 1983). When people are drawn, they are looking at the viewer, and are usually smiling. Objects and figures sit on an invisible baseline and every single object is separate from each other. (Lowenfeld & Brittain 1987.)

The most general changes are exaggeration and enlargement of important body parts and omission of less important parts. These changes appear particularly when the child is asked to draw a human figure fulfilling a task. In which case, body parts important in the activity may be emphasized and unnecessary parts may be totally missing. Children’s drawings begin to reflect things they know and experience (Jarasto & Sinervo 1998) (See Figure 3, on page 29). A child’s active knowledge about the environment, seen in her/his drawings, reveals the level of her/his understanding of the surrounding world.

At the Dawning Realism Stage, between the ages of 8 and 10 the ability to perceive space develops. Between the ages of 6 to 10, the child’s drawing becomes more realistic and corresponds increasingly to reality. Naturally, a certain creativity and fantasy diminish. At the age of eight the child chooses foreground as a baseline and positions skyline to structure the space. In HFDs the proportions of head and body become specified, drawings become more regular and are expressed with more details (See Figure 4, on page 30).

In the Pseudo-Naturalistic Stage, children try to create naturalistic drawings. Reflection as a cognitive skill at the age of 12 makes children more self-conscious and critical of their drawing. Readiness to draw depth, different perspectives and space as three-dimensional progresses gradually (Lowenfeld & Edwards 2000)
(See Figure 5 on page 30). According to Koppitz (1984), the structure of human figures changes little after the age of 11 or 12 years, unless the individual is unusually artistic.

Even though, the theory divides the drawing ability as progressing from one stage to another, it is difficult to draw a strict line to the point where one stage of development ends and another begins. The stages are not separate instead they are founded on earlier experiences. Both the mutual interaction of the child’s development in reasoning and drawing and the child’s experiences from people around her/him as well as the “pictures” available in the environment significantly influence children’s drawing. (Thomas & Silk 1990, Brotherus et al. 1999: 63.)

Fig. 1. Scribbling Stage, A boy, 2 yrs.
Fig. 2. Pre-Schematic Stage, A girl, 3 yrs “Daddy”.

Fig. 3. Late Pre-Schematic/Early Schematic Stage, A girl, 4 yrs, 6 months “Horse and Rider”.
Fig. 4. Dawning Realism Stage, A girl, 7 yrs.

Fig. 5. Early Pseudo Naturalistic Stage, A girl, 10 yrs, 7 months, “Circus”.

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Intertwining of cognitive and drawing development

Children’s level of cognitive and drawing development has implications for their capabilities to represent their experiences and cues about their understanding of events around them. There are predictable, observable, and measurable stages in drawing behaviour that coincide with stages of cognitive and motor development.

Table 1. Stages of children’s cognitive and drawing development.

| Stage of cognitive development (Piaget) | Stage of drawing development (Lowenfeld) | Approximate age range | Implications for expressions through drawings*
<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Later part of Sensorimotor period, beginning of Pre-operational</td>
<td>Scribbling Stage (First Stage of Self Expression)</td>
<td>18 months to 3 years old</td>
<td>Child’s thinking is kinaesthetic, eye-hand coordination improves along with age, the child begins to recognize the edge of paper and draw shapes, at first disordered, uncontrolled markings, later longitudinal controlled repetitions of motions, further exploring of controlled motions demonstrating the ability to more complex forms (circular), the child tells stories about the scribble. At the age of three the first representational attempt to draw a human figure appears, usually with a circle for a head and two vertical lines for legs.</td>
</tr>
<tr>
<td>Pre-operational</td>
<td>Pre-Schematic Stage (First Representational Attempts)</td>
<td>4 to 7 years old</td>
<td>Symbolic thought is emerging. Ability to classify and see relationships. The child finds a “schema”, a definite way of portraying an object. Space is primarily related to the child’s own body, but when portraying something important it can be modified. Common things from environment appear (sun, houses, flowers…), everything sits on a baseline. Colours are selected on a whim.</td>
</tr>
<tr>
<td>Pre-operational</td>
<td>Schematic Stage</td>
<td>7 to 9 years old</td>
<td>Visual symbols/true schemata for human figures, houses and animals appear. These are often fairly standard e.g. a person with a hairstyle, arms and legs; a house with triangular roof; a definite base line is apparent, colours reflected as they appear in nature. Exaggeration between figures often to express strong feelings about the subject.</td>
</tr>
<tr>
<td>Concrete operations</td>
<td>Dawning Realism Stage (also known as the Gang stage)</td>
<td>9 to 12 years old</td>
<td>Tendency to shift away from egocentric thinking and to consider the thoughts and feelings of others, understanding of relationships, cause and effect. Schematic generalization no longer suffices in expressing reality. Tendency to express things as they really look is seen in the appearance of more details for individual parts. Self awareness to the point of being extremely self-critical. Awareness of the space between the base line and sky line.</td>
</tr>
<tr>
<td>Concrete operations</td>
<td>Pseudo-Naturalistic Stage (Stage of Reasoning)</td>
<td>12 to 14 years old</td>
<td>The product becomes most important to the child. The end of drawing as spontaneous activity due to a need for perfection and adult-like naturalistic drawing. Three dimensional effects achieved along with shading and use of subtle colour combinations or by diminishing the size of objects that are further away.</td>
</tr>
<tr>
<td>Formal operations</td>
<td>Adolescent artistic development (The period of decision)</td>
<td>14–17 years old</td>
<td>Ability to think of large systems, reason about ideas, impossibilities and probabilities. Masters broad abstract concepts. May be unwilling to draw at all at this stage.</td>
</tr>
</tbody>
</table>

According to Lowenfeld (1947) children's development through drawing is analogous to the process of organizing thoughts and the development of cognitive abilities. The stages of Piaget's (1959) theory of cognitive development correspond largely to Lowenfeld's stages of drawing development. The drawing becomes more representational and detailed along with the development of motor skills and cognitive functioning (Lowenfeld & Edwards 2000). Table 1 gathers together the stages of children's cognitive and drawing development.

2.2.3 Children and memory

One area of concern regarding the interviewing of children is the age at which they can remember past events, and how much and for how long they can remember and communicate these past events with an interviewer. In the late 1970s and early 1980s, research on memory development began to focus on children’s memory for events in which they had been participants (Pipe et al. 2004). In the area of memory development research has been directed toward finding out how children process, store and retrieve experiences (Fivush et al. 1991, Nelson 1993, Steward 1993, Nelson & Fivush 2004).

At the early ages of two and three, children begin to narrate events and experiences in relation to themselves which have been organized autobiographically in memory. "Autobiographical memory" (AM) or "personal memory" refers to explicit recollections of past events and episodes in a personal history coded with respect to time and place (Howe et al. 1994, Sutton 2002). Brewer (1996) offers a more precise working definition and sees AM as a reliving or revival of a person’s own past phenomenal experience, with the additional knowledge that the person had that experience before. Perner (2000: 307) regards AM as a more sophisticated capacity, which "entails a reflection on past events as past events, as events that one knows (conscious, explicit memory) and as personally experienced (episodic memory)." Episodic memory concerns information specific to a particular context and is used for more personal memories, such as the sensations, emotions, and personal associations of a particular place or time. AM is generally viewed as either equivalent to, or a subset of, episodic memory.

The development of personally coded memories is related to the emergence of the self-concept, not specifically to isolated structural (neurological) or functional (coding, storing, retrieving) change in long term memory. Knowledge of oneself as an independent entity enables the organizing of experiences in memory as personal. (Howe et al. 1994.) Stern (1992) states that, from childhood the human
mind seeks explanations for the things happening to oneself. A human needs to search for the meaningful particulars of various experiences of life and combine them in an entity. A narrative is a means of formulating these entities.

There is strong evidence that children’s memory improves with age (Cowan et al. 1999) and even a young child can recall events. Children’s development of memory is linked to the vocabulary spurt children experience at a young age and as a consequence of language development. Approximately at the age of four a child has enough mental capacities and concepts to construct understandable entities out of parts and unite memories of separate events to each other. Even 4-year-olds are able to remember salient functions and important details of an event. Children begin to accumulate more childhood memories that start to become a part of the self account and can be re-enacted in adulthood. (Nelson 1988, 1992, Price & Goodman 1990, Ceci et al. 2003.)

According to Pipe et al. (2004), children are capable of providing accurate information about their experiences, although language development, emotional factors, individual differences and event characteristics affect children’s willingness to talk and to be cooperative. The effects of age and time on memory are common but not inevitable. Knowledge and understanding affect the quantity of remembering of both children and adults. With respect to event memory, recent studies (e.g. Greenhoot 2000, Sutherland et al. 2003) suggest that children with more knowledge about an experienced event are able to recall later more details about that event than children with less knowledge. Inadequate verbal memory performance does not necessarily relate to weak memory in a child, for children can produce lots of non-verbal memory representations (Simcock & Hayne 2003).

### 2.2.4 An adult’s chances of catching a child’s experiences

Webster’s Encyclopedic Unabridged Dictionary (1994) defines an experience as an entity of cognitions gained through observations. It is related to everything that is observed, understood and remembered. The foundation of experiences lays in consistent fashion of being in relation to the world (Perttula 1995a: 29). According to Perttula (1995a: 19–20) an experience signifies the real content of a situation in life, which manifests itself as a certain relationship of meanings in a human mind. Persons, owing diverse experiential background define a situation in various ways, give the situation a different meaning whereas, consciousness always includes the fact, that an experience is always an experience of something.
According to Stern (1992), the world of experiences is the present moment as it manifests itself in time. Experiences are usually contemporaneous, and they consist of sensations, feelings, thoughts and activities. A child builds their world of experiences perpetually in terms of a specific theme or context by choosing things that they think are suitable. At the same time, a child takes advantage of things life has accidentally thrown their way in order to develop old themes and create new ones. The world of experiences is an internal matter and, when talking about it, a child in a way transforms perceptions, feelings and moods into external activities. In other words, a child’s interpretation of their experiences influences their behaviour (Hughes 1989).

According to Colaizzi (1978), when objectively reviewed, an experience is not inside a person instead it always manifests itself in behaviour towards the world and other people. In conclusion an experience is objectively true to the person himself, and to others. An experience is not an internal state on the contrary it is a way to attend the world. This way to attend the world is existentially significant. (Colaizzi 1978.)

In any case, it is not easy for an adult to apprehend children’s emotions and experiences. Many realities of life make this complicated or even prevent any such understanding. However, an implicit belief in the possibility of adults understanding children’s experiences is associated with the examination of these realities. Hellsten (1992) uses the concept of “child-like quality” when referring to a child who may be inside a person regardless of their age. The typical features of a child-like quality include feelings, needs, simplicity, and being puzzled and amazed. But these features need not be excluded from adulthood. The chance of understanding children’s experiences may lie in the child inside the adult. In fact, this could be considered an absolute prerequisite for apprehending children’s experiences. Every adult has personal experiences of the way a child comprehends the world. Therefore, the basis for apprehending children’s experiences is the adult’s experiences of being a child. Making interpretations and assumptions of children’s experiences requires a child-like quality in the researcher.

In fact, when eliciting experiences we examine matters which emotionally touch a person. It is quite clear that, as adults, we will never see the world through a child’s eyes; rather, we will see it through various layers of experience. Adults chances of eliciting children’s experiences can also be sought in their adulthood. (Liljeström 1982.) An adult recognizes his own humanity as a basis for understanding another human being (Douglas 1985). Adults’ knowledge and experience help them in understanding children. Acknowledge of children and of childhood in
general activates an interpretative frame of reference (Liljestöm 1982). According to the view that has become established more and more in the field of child research, there is no abstract independent child, but childhood can be examined and understood only with the help of paradigms common to both children and adults.

2.3 Summary of the origins of the study

Conducting research with children, especially interviews around distressing events, requires researchers to understand the development of narrative competences in children. Likewise, they have to appraise the overall developmental age of the participating children. Children are equal to adults but are nonetheless different. For this reason I present the summary of the origins of the study in the end of section 4 (Methodology) because the prejudgements I have, contribute to my orientation to the phenomenon studied and to the children who collaborated with me, as well as to the methodological choices I employed.
3 Aims of the study and tasks for research

Traditionally an adults’ perspective has dominated in research on ill children (Docherty & Sandelowski 1999, Woodgate 2001, Forsner et al. 2005, Neill 2005), even though children can reliably cascade their experiences (Carter 2002a, Kiernan et al. 2005) and children’s own experiences can elicit other dimensions of information than when questions are phrased from adults’ perspective and appreciations. Despite all this, children’s voices do not figure significantly in health literature. The general picture in the literature on children’s medical encounters in clinics suggests that children play only a minor role in contributing their experiences and are not actively involved in the encounter (van Dulmen 1998, Carter 2002b, Alderson et al. 2006).

Starting from the concrete in a scientific investigation, in this case from children’s experience of pain, can reveal earlier unknown dimensions of child pain and children’s pain management. Giving children, who have experienced pain and hospitalization, a voice about their perceptions, can highlight this less investigated perspective of their pain and management.

The ultimate aim of this scientific research was to illuminate hospitalized children’s pain experiences, and their views of pain management in hospital settings as described by children themselves. Further, the aim was to improve pain assessment and management in hospitalized children by approaching the question from children’s point of view and from their needs. The findings of the study will provide research–based knowledge for doing research with children as well as for healthcare professionals in assessing and managing children’s pain in a more holistic and child-centred way. The research involves five research tasks with the following specific aims:

1. To identify and describe methods in qualitative child interviewing (Paper I).
2. To identify and describe the sources and causes of pain experiences in 4– to 11 year-old hospitalized children (Paper II).
3. To identify and describe 4– to 11 year-old hospitalized children’s pain descriptions and views of the purpose of pain (Paper III).
4. To describe and understand 5– to 11 year-old hospitalized children’s pain through their pain drawings (Paper IV).
5. To identify and describe the pain alleviation methods young children use themselves and their expectations of other’s help, when managing the pain experienced during hospitalization (Paper V).
4 Methodology

4.1 Study design

In producing understanding of pain and pain management, different kinds of methods from various scientific traditions, as well as an understanding of human needs on many various levels, are needed. This thesis can complement the current knowledge through its data collected from young hospitalized children in order to clarify and better understand the contents of children’s experiences with pain. In this study I used three phases of data collection strategies: a literature phase, a qualitative child interviewing phase and a pain drawing phase. The multiple data collection methods helped to increase the understanding of the phenomenon being studied. My aim was to acquire trustworthy data to interpret and share children’s experiences with pain in order to yield new understanding.

The study consists of five papers. Paper 1 discussed the methodological considerations of qualitative child interviewing, Paper 2 described the sources and causes of children’s pain experiences, Paper 3 dealt with children’s pain descriptions and views on the purpose of pain, whereas Paper 4 examined the children’s drawings of pain and Paper 5 focused on the children’s experiences of pain management. The participants, data and methods of analysis as well as the original publications are summarized in Table 2.
Table 2. Participants, data, methods of analysis and original publications.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Data</th>
<th>Method of analysis</th>
<th>Original publications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paper 2</td>
<td>44 hospitalized four to 11-year-old children in four wards of Oulu University Hospital</td>
<td>Qualitative child interview</td>
<td>'I had this horrible pain': the sources and causes of pain experiences in four to 11-year-old hospitalized children (2004)</td>
</tr>
<tr>
<td>Paper 3</td>
<td>44 hospitalized four to 11-year-old children in four wards of Oulu University Hospital</td>
<td>Qualitative child interview</td>
<td>'The most disgusting ever' – Children's pain descriptions and views of the purpose of pain (2006)</td>
</tr>
<tr>
<td>Paper 4</td>
<td>37 children who were inpatients at a university hospital in four wards and participated in an interview study, aged from 5 to 11 years, 22 healthy children from a day-care centre and a local elementary school, aged from 5 to 11 years</td>
<td>Pain drawings A child's interpretation of the drawing</td>
<td>Hospitalized children drawing their pain: The contents and cognitive and emotional characteristics of pain drawings (2008)</td>
</tr>
<tr>
<td>Paper 5</td>
<td>44 hospitalized four to 11-year-old children in four wards of Oulu University Hospital</td>
<td>Qualitative child interview</td>
<td>'You just have to make the pain go away'- Children's experiences of pain management (2008)</td>
</tr>
</tbody>
</table>
4.2 Methodological approaches to studying children

One of the intellectual virtues embodied in the process of carrying out research is the pursuit of truth. In the exchange of experiences, understanding and knowledge new truths can be revealed. Ricoeur (1965) compares truth to environment and states that seeking the truth is a never ending task. According to Weil (1994) seeking information does not lead us nearer to the truth. Seeking the truth means a longing for the real world and direct contact with it.

4.2.1 Children as research participants

In this section I discuss the issues surrounding the engagement of children as participants in a research project. My focus is on children’s rights in relation to expressing their views in matters affecting the child. In addition, I discuss questions about access/gatekeepers, providing or withholding access to the child and consider the question of consent/assent for the child to participate or the researcher to ask the child to be involved in research.

The World Medical Association declaration of Helsinki (1964), amended by the 52nd World Medical Assembly held in Edinburgh in 2000, provides a standard of international ethics in research involving human subjects, and it also examines the issue of children as subjects in relation to informed consent/assent. The latest revision requires that, in the future, special grounds should be demonstrated for excluding children from such research (WMA 2000). Coad & Lewis (2004) define consent as a permission for the child to be interviewed or the researcher to ask to interview the child. The permission can be given by the child or by another on the child’s behalf. Assent, instead, is a child’s agreement to participate when another has given consent. According to Alderson (1995) informed consent/assent means that the person has received information about the chance to participate, the person knows about the right to withdraw at any time, the person knows about her/his role as a participant and the person knows about the intended outcomes of the research.

The United Nations Convention of the Rights of the Child (UN 1989), Article 12, says that children, like adults, have the right to be consulted and to express their views freely in all matters affecting themselves. In addition to international and national regulations, a number of professions have their own international codes, as well as instructions providing guidance within their own countries. In health care ethics, the principle of respect for the dignity and autonomy of the individual means that people should be respected and that they have the capacity of
self-determination. If autonomy is assessed as having capacity to reason and make decisions, even young children can do this and give informed consent if they are given relevant information, as well as time to negotiate and the opportunity to do so (Lowden 2002, de Leeuw et al. 2004).

There is a longstanding moral and legal tradition supporting parents as the preliminary decision-makers for their children, including the right to make decisions about their participation in research. Today, however, the legitimate role of children in decisions about research participation is recognized. However, examining, understanding and following international and national laws and policies giving children the right to express themselves are of uttermost importance when involving children as research participants. The requirements will vary from country to country, and there may be cultural differences that also have an impact. Working with children requires particular sensitivity not only to protect the children, but also to protect the researchers involved (Coad & Lewis 2004).

When a child is to be involved in a research project someone acts as a gatekeeper, providing or withholding access to the child. The intention of gatekeepers is to act as protectors but it is possible that they may deny children opportunities for participation or coerce them into participating. The first level or direct gatekeeper in most cases is the parent or the child’s carer. On the other hand someone else may act as the second level or indirect gatekeeper to the parents or carers. In the health care context ethical committees also act as gatekeepers. Depending on the context and the focus of the research gatekeepers may, also or instead, be social service agencies or head teachers. (Harden et al. 2000, Coad & Lewis 2004.)

In the research context, there has been much debate on the question of what age children can fully consider the implications of participation in a research project (e.g. O’Donnell 1998, Strasburger 1998). Masson (2005) defines competence as the level of understanding needed to make decisions. Regardless of the prevailing debates, a lack of competence does not remove a child’s right to express a view.

Regulations and codes do not necessarily cover all the circumstances, neither do they give a formula to make mature ethical decisions, but they address the key issues when research is conducted with children as participants (Grodin & Glanz 1994, Kodish et al. 1998, Greig & Taylor 1999, Alderson 2000, Lowden 2002). In accordance with good research ethics, participants need to know that participation is voluntary and that they have a chance both to refuse and to interrupt the participation at any time (Burns & Grove 2004). Ethical activities emphasise respect for other people. Unlike in daily interaction between children and adults, in research
on children and when children possess the information the researcher needs, the child informants ought to be asked for their permission and they need to set the rules. Those who do research with children need to consider what this means in practice and how it affects the fieldwork. (Graue & Walsh 1998, Alderson 2000, Lowden 2002.)

In the literature on the methodological and ethical issues in nursing there has been some consideration about conducting research with children and about different methods for data collection such as interviewing (Coyne 1998, Faux et al. 1988, Kortesluoma et al. 2003). In human science based nursing research methodology there is a clear expectation that the voices of marginal groups such as children are represented (Baumann 1996, McCance et al. 2001, Carter 2004, Coad & Lewis 2004). This requires choosing methods which successfully elicit children’s views and experiences and young children are viewed as partners in research about lived experiences. Baumann (1996) notes, that viewing children in this way requires a considerable revision of the view of children, adopted in many traditional theories of childhood and in research with children.

According to Kirk (2007) research with children has taken for granted a child-adult distinction. Nursing research on child health is based on the psychological notion of individual development and researchers in nursing science paid little attention to the sociology of childhood. Moreover, there is little debate on the need for using different methods when carrying out research with children or with adults (Woodgate 2001, Punch 2002a, Kirk 2007). From the point of view of this study, it was important to choose methods appropriate for the children involved, their social and cultural context and the research tasks, as well as the interpretation of data.

4.2.2 Qualitative child interviewing as a medium of scientific knowledge

The use of interviews is both historically and currently the most favoured technique in gathering data for research purposes, although children are generally silenced in research. Children have been represented as passive when their experiences of health and illness have been considered, so their voice in research has not been sought (Sartain et al. 2000). In social science children are now seen as active in the construction and determination of their social lives (James & Prout 1997) and in current nursing science there is a tendency to involve children as active participants in research (Hill 1997, Sartain et al. 2000, McCance et al. 2001, Carter
Researchers such as James and Prout (1997) and Hutchby and Moran-Ellis (1998) have anticipated the question of children’s social competence in the social studies of childhood. These studies indicate that children should be taken seriously as social agents. In order to explicate children’s views ‘from within’, these studies have adopted various approaches (from ethnography) such as one-to-one interviews and the analysis of children’s documentary accounts (e.g. drawings) of their lives (James & Prout 1997, Hutchby 2005). Indeed, many authors have offered guidance on a range of interviews: including personal, group and family interviews (Faux et al. 1988, Steward et al. 1993, Mahon et al. 1996, Coyne 1998, Miller 2000b, Sartain et al. 2000, Ästedt-Kurki et al. 2001, Maijala et al. 2002, Morgan et al. 2002, Callery et al. 2003, Kortesluoma et al. 2003).

The interview is the method for capturing stories for research purposes. I chose the qualitative open-ended interview as a method of data collection (Paper I) because it generates narratives or small stories which open up an opportunity to tap into children’s experiences (Mishler 1986, Riessman 1993) and because it allows the participants to give responses freely. There are various definitions of narratives (Polkinghorne 1988, Denzin 1989, Riessman 1993, 2002, Mishler 1995, Frank 2000). Polkinghorne (1988: 13) defines narrative as referring ‘to any spoken or written presentation’. This means, according to Polkinghorne (1988: 6), that the general term narrative ‘becomes synonymous with the primary linguistic expressions that make up qualitative research projects: it is used to refer to the data form of field notes or original interview data and their written transcripts’. It is worth to noting that authors interchange the terms narrative and story. Denzin (1989: 37) encapsulates the definition and characteristics of narrative/story as follows: a ‘narrative’ is a story that tells a sequence of events that are significant to the narrator and his or her audience. A narrative as a story has a plot, a beginning, a middle and an end. It has an internal logic that makes sense to the narrator. Every narrative describes a sequence of events that have happened. However, I prefer the term of story in the context of children’s accounts of their pain experiences because according to Frank (2000) ‘people do not tell narratives, they tell stories’. The aim of my interview process was to elicit children’s personal stories of their pain experiences. The nature of my study directed the format I followed. The method in my study could be described as unstructured interview in which I had a list of topics according to my research aims and I had freedom to alter the sequence and to probe for more information depending on each child’s response. In other words, I could move freely the conversation in any direction of interest that came up.

Although qualitative interviews require well-developed communication skills, they potentially and effectively give children a voice. A basic requirement in child-centred research is that the interviewer/researcher is sincerely interested in the child’s response. That is why, identifying the kind of open-ended questions that are more likely to produce stories, is of most importance. Moreover, interview schedules should be well-planned to ensure the maximal use of open-ended questions (Moston 1990, Riessman 1993, Dockrell et al. 2000, McCance et al. 2001).

4.2.3 Using drawings as a medium of scientific knowledge

The literature on drawing development emphasizes that a young child draws what she/he knows (their "idea" of the object). Transition takes place between 4 and 7 years of age, at which stage a child rather draws what she/he sees. The child’s graphic expression captures her/his thoughts symbolically on paper coloured by her/his feelings. This makes drawings so significant as expressions of personality and useful for the identification of emotional problems in children. (DiLeo 1970, Thomas & Silk 1990, O’Malley & McNamara 1993, Carroll & Ryan-Wenger 1999, Picard & Durand 2005.)

Expressive techniques, such as drawings are popular projective techniques, based on the assumption that drawings reflect a child’s self-concept, attitudes and conflicts. Children interact with their world and often use drawing as a medium to describe their experiences. Projective techniques require participants to generate a response (e.g. a drawing) following open-ended instructions (e.g. “Draw a picture that contains a lot of pain”) (Paper IV). In addition, most projective techniques permit respondents considerable flexibility in the nature of their responses (Lilienfeld et al. 2000). They also represent emotions or thoughts that children may be unable or unwilling to express verbally (Fury et al. 1997, Ryan-Wenger 1998). Moreover, Barrazza (1999) explains that the drawings of children are useful tools in evaluating their perceptions of their environment. Drawings can be used to assess development of psychological well-being, as a source of data or to open up communication with children (Baumann 1994, Bricher 1999).

Children’s drawings have traditionally been used in the fields of psychiatry, psychology and education (Goodenough 1926, 1928, Harris 1963, Kopittz 1968, 1984, Kellogg 1969, Burns 1970, DiLeo 1970, 1973, Machover 1980, Buck 1981). They have long been used as projective measures of children’s personality charac-
teristics such as attitudes, thoughts and feelings (Poster 1989), as well as needs and
tears because traditional methods, such as questionnaires and directed interviews,
are often adult-centred, adult-dominated, and biased (Bradding & Horstman 1999).

Drawings requested by the researcher are a form of communication between
the child and the researcher. A drawing can provide information on children’s
developmental status (Koppiz 1968, Kellogg 1969, Gardner 1980, Lowenfeld &
Edwards 2000) and emotional functioning (Goodenough 1926, 1928, Buck 1948,
(Goodenough 1926, 1928, Goodenough & Harris 1950, Harris 1963),
House-Tree-Person (Buck 1948, 1981), Draw-a-Person (Machover 1949, 1953),
Human Figure Drawing (HFD) Test (Koppiz 1968), Kinetic Family Drawing
(Burns & Kaufman 1970, Burns 1982), The Child Drawing Hospital (CD:H) (Clat-
worthy et al. 1999a) and Draw-a-Person: Screening Procedure for Emotional Dis-
turbance (DAP: SPED) (Naglieri et al. 1991) have been well supported as means
of evaluating the emotional status of children in various life situations. Drawing
acts also as a mode of communication for children and helps them to quickly com-
municate their concerns and problems, thus enhancing interaction between the
child and the researcher (Malchiodi 2001). Therefore, on this basis, I hypothesized
that the same might be true for those hospitalized children experiencing pain who
participated in this study.

4.3 Data, data collection and analysis

In this chapter I will describe the selection of the research participants and explain
how I carried out the data collection and data analysis. The different phases of the
study are presented in Figure 6.
Fig. 6. Phases of the study.

### 4.3.1 Selection of research participants for interviews

The permission to carry out this study was granted by the Board of Ethics at the Faculty of Medicine of the Oulu University. I carried out the study in four wards at the Oulu University Hospital, Department of Paediatrics and Adolescence and secured approval from the medical doctors in charge of these wards. I selected the participants using the purposive sampling technique (Coyne 1997, Burns & Grove 2004). This kind of sampling does not focus on generalisations which can be developed by similarities instead it seeks out specifics that give the data its unique flavour (Lincoln & Guba 1985).

The selection criteria were that the children should be aged between 4 and eleven. I excluded children younger than 4, because eliciting information from
them would require an altogether different approach. Similarly, I excluded children over 11, because interviewing them is not as problematic as interviewing younger children. Furthermore, children aged 4-11 are the most challenging because of their linguistic development. Moreover, the children should have an ailment or disease that caused hospitalization at the time of the interviews. In addition, the child was to participate voluntarily. Children who met the criteria were selected to participate in the research by the nurses familiar with them. The selection of participants was influenced both by the above criteria and by the nurses’ assessment of the children’s ability to interact with an adult they did not know. After the nurses had chosen the children, I asked their parents or custodians to give written consent for the child to be interviewed (e.g. Brooks & Kendall 1982, Rheingold 1982, Broome 1999, Lindeke et al. 2000, Rossi et al. 2003, Parekh 2006). All the parents and custodians gave consent for their children to be interviewed. Out of respect for the children and for their vulnerability, the nature of the study and their right to refuse I discussed with the children in language they could understand and I asked the children for their informed assent (assent = a child’s agreement to participate) (e.g. Greig & Taylor 1999, Alderson 2000, Lowden 2002, Miller & Nelson 2006) after I had obtained consent from their parents. In practice, I requested the permission for the interviews in the ward, or by phone when arranging an appointment for an interview. Only two children refused to participate in the interview study.

Forty-four 4 to 11 year olds agreed to participate. They had all been admitted for different reasons into four different wards. Table 3 shows the distribution of the health problems of the interviewed children.

Table 3. Health problems of the interviewed children (f, %) (n = 44).

<table>
<thead>
<tr>
<th>Problem</th>
<th>f</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problems of locomotive systems</td>
<td>18</td>
<td>41</td>
</tr>
<tr>
<td>Internal-surgical problems</td>
<td>11</td>
<td>25</td>
</tr>
<tr>
<td>Tumours</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Hematological diseases</td>
<td>6</td>
<td>14</td>
</tr>
<tr>
<td>Diabetes</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Burns</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>44</td>
<td>100</td>
</tr>
</tbody>
</table>

A small majority of the interviewed children were girls (61%). Of the interviewed children 48% (f=21) were aged 4-7 and 52% (f=23) 8-11 years. The average age of the participants was 8 years and 3 months.
22 of the children had undergone an operation. Some of the children were in hospital either for examination or for preventive/conservative care. All had undergone several different examinations and treatments.

The children had very varied experiences of hospitalization, in both duration and frequency. Some of the interviewed children did not have earlier experiences of being hospitalized, and some only had experiences of outpatient treatment. Some of the children had been hospitalized frequently, up to seven times. At the time the interviews took place, the children had been in hospital from between one day to 26 weeks.

4.3.2 Obtaining and analysing the interview data

In this section, I focus on describing the data collection by qualitative unstructured child interview. Moreover, I describe content analysis as a research method and my choices in analysing the interview data.

Conducting the Qualitative Child Interviews

I chose a qualitative research approach, because it best answered the purposes of this research. Qualitative research data can be obtained in numerous ways. In this study I offered children the chance to take part in a qualitative child interview (Paper I) with open-ended questions which enabled the children to generate their own alternatives and did not restrict their answers. To foster an interpretive openness to the children’s experiences, I used generative or trigger questions based upon the study aims which gave the interviews their focus.

I carried out all the interviews either in a patient room or at the doctor’s office bearing in mind that when interviewing children the interview technique is of importance (Miller 2000a, Woodgate 2001, Kortesluoma et al. 2003). According to Woods (2005), it is important that adult voices, in this case my voice as a researcher did not overshadow what the children have to say. Therefore I recognised children as expert informers regarding their own experiences and perspectives. I conducted the interviews using child-centred techniques, with particular attention to building rapport between the child and the researcher (Donalek 2005). This meant using 20-60 minutes to build up a trustful rapport with the children by playing with them. I put an effort to avoid an inherent asymmetry of power known to be a risk in traditional interviewing. Shifting the balance on to the children enables them to tell their experiences and use their own words. The interview
questions were open-ended and I clarified uncertainties by follow-up questions. The interviews lasted 22 minutes on average and were tape-recorded. To supplement the interview, I and each child listened to the tape at the end of the interview. None of the interviewees wanted to add or revise anything.

*Content Analysis as a research method*

There are many ways of analysing qualitative data. The selection of the method(s) depends on the type(s) and length of material to be analyzed, and researcher’s preferences and technological capabilities. The chosen method should also be suitable for the purposes of the study. It is significant that the participants of my study were children, whose ability to focus their attention deliberately on pain and the experience of pain depends on their cognitive developmental stage, and their ability to think. It is difficult for children to think and talk about something else other than the present. Along with cognitive development, children’s capacity for analytical thinking and their ability to express their thoughts with language develop continually (Genishi 1988, Bochner & Jones 2003).

Given the focus of this study, the fact that the participants were children, the type of data gathered and the quality of the research questions, content analysis seemed an appropriate method for analysis (Kelly & Sime 1990, Burns & Grove 2004, Graneheim & Lundman 2004, Hsieh & Shannon 2005) (Papers II, III, V).

The history of content analysis dates back to 18th Century Scandinavia (Rosengren 1981, Hsieh & Shannon 2005). Historically it was a research tool dealing with “the objective, systematic and quantitative description of the manifest content of communication” (Berelson 1952: 18), and it initially was limited to studies that examined texts for the frequency of the occurrence of identified terms (word counts). According to Morgan (1993) this approach was referred to as quantitative analysis of qualitative data. Over time it has expanded to also focus on concepts rather than simply words and to include interpretations of latent content (de Sola Pool 1959, Graneheim & Lundman 2004).

Currently, there are two different uses of content analysis: a quantitative approach used by many authors from a wide array of fields (e.g. communication and media research, marketing, literature) and a qualitative approach often used in nursing and education research. Content analysis is a flexible method for analysing text data (Cavanagh 1997) and has been applied to a variety of data and to various depths of interpretation. In health care research, content analysis has been recognized as a qualitative analysis method and has lead to its popularity and increased
Qualitative content analysis can be used to describe content and underlying messages in human communication and has been used in the analysis of narrative responses, open-ended questions and interviews, as well as focus groups, observations, or printed media such as books, manuals and articles (Kondracki et al. 2002). In nursing research it has been used to analyse data on children’s experiences connected with illnesses and hospitalization (e.g. Runeson et al. 2002, Sorsa et al. 2006).

The goal of content analysis is “to provide knowledge and understanding of the phenomenon under study” (Downe-Wambolt 1992). Rather than being a single method, there are three approaches to qualitative content analysis to interpret textual data: conventional, directed and summative. In all of these approaches the basic coding process is to organize large amounts of textual data into far fewer categories using a similar analytical process but they all take a different tack in developing the initial codes. (Hsieh & Shannon 2005.) In this study I use conventional content analysis to describe a phenomenon and to derive categories from data during data analysis and I also avoided the use of preconceived categories (Kondracki et al. 2002). I created the categories and names for categories from the data. Mayring (2000) labels this as inductive category development. In my study I regard content analysis as a research method for subjective interpretation of the content of the textual interview data conducted by the systematic classification process of coding and identifying categories or themes.

In this research study I transcribed the tape-recorded interviews verbatim and analysed all the data (Papers II, III, V) including field notes and interview transcripts using inductive qualitative content analysis (Miles & Huberman 1994) in an attempt to produce a detailed and systematic list of categories arising from the interviews. After reading through the interviews, the second step was to re-read the data and to identify the unit of analysis – this meant that I examined the data line-by-line to identify units of information – which I defined as a complete thought, ranging from one word to several sentences. I chose expressions or sentences for conveying a clear meaning relevant to the research to serve as a unit of analysis (Downe-Wamboldt 1992). I formulated the derived units in the words used by the participants themselves. Unitization served as a basis for the third step of defining categories. The obligatory task of categorizing involved bringing together the units of data that related to the same content (Lincoln & Guba 1985). In categorizing the data, I grouped issues denoting the same feature into the same category and label. The label described the contents of the category (Papers II, III,
V). The progression of the analysis necessitated an ongoing dialogue with the data and to revisit the earlier stages of the analysis over and over again.

Understanding speech is completely context dependent (Tornéus 1991). The interpretation and understanding of a sentence are based on the context in which the conversation occurs. Due to this, and because the context in which the pain is experienced essentially affects the pain experience itself, I did not want to separate the children’s pain descriptions from their context. Instead, when answering to the third research task (Paper III), I examined these descriptions always in the context in which each individual experience had emerged. I placed the children’s statements in the categories constructed from the sources and causes of the children’s pain experiences (see Paper II), according to the connotation and context of each statement. I included every single statement in its context to the analysis. (An example of children’s pain descriptions in the context in which the experience had emerged, Appendix 1.)

In order to further clarify the third research task, I examined the children’s descriptions of their pain experiences and separated the descriptions from their contexts, because I aimed to categorise all the children’s statements in order to sort out the richness and multidimensionality of their vocabulary when describing their pain. In spite of the separation of the statements from the context, the context has affected my interpretation of their meaning and thus my categorisation. Similarly, I examined the children’s individual statements about the purpose of pain. From a variety of statements I built up subcategories. On the basis of the similarities and differences, I defined the main categories.

I included additional information in the transcribed interview data such as other communication related to the interview situation and the observations I made about the child during the interview. Briefly I described the atmosphere of the interview as I thought these perceptions useful for subsequent data analysis, even though in this phase the precise meaning of this knowledge from the viewpoint of the study as a whole was unclear to me. In any case, I assumed that my perceptions might help in conceptualising the children’s experiences. (An example of an interview intuitively transcribed by content areas according to meaningful statements is in Appendix 2).

Figure 19 on page 85 demonstrates the categories based on the analysis and formulated inductively from the data.
4.3.3 Obtaining and analysing the pain drawings

In this section, I focus on describing drawing as a research method and methodology. I present the collection of children’s drawings (as a method) as expressions of their pain experiences. Moreover, I examine the three different approaches I used in analysing the drawing data (contents, cognitive drawing quality and emotional drawing quality) (Paper IV).

Drawing as a research method and methodology

I applied Harding’s (1987) definitions in my discussion of drawings as a method and methodology. She defined method as a technique for gathering evidence and methodology as a theory and analysis that informs how research does or should proceed. She also saw method and methodology intertwined together and interrelated with epistemology. An epistemology is a theory of knowledge. It answers among others questions such as who can be a knower (can children?) and what kind of things can be known (can subjective truths be seen as knowledge?) (Harding 1987).

My study on children’s pain drawings stems from an epistemological base which considers knowledge (about pain experiences) as variable and changeable. From this perspective, methodologically, drawing can be seen as a goal directed behaviour taking place both in time and place and thus studied from two different perspectives. Firstly, from a product oriented approach drawings can be studied from the “what” a person draws. Methodologically this means that drawings can be seen as visual products. Secondly, from the process oriented approach drawings can be studied from the “how” the drawing is drawn, that is to say from the process of production. (Vinter 1999, Guillemin 2004.) Because the word drawing is both noun and verb, in this research I regard drawing both as a product and the process of drawing.

Drawing is not a spontaneous action but rather an intentional process involving projection and introjections by the individual. As children grow, they associate various sensations, perceptions, and emotions with their bodies. As a result, drawing provides a natural vehicle for the expression of one’s needs and conflicts (Machover 1949). Every child’s drawings are unique, as are their contents and ways of drawing, the use of graphic illustration, the strength and direction of lines, the use of space and colour reflect important emotions, thoughts and fears (Naglieri et al. 1991, Di Gallo 2001). The drawings tell of a child’s attitudes,
self-image and inner experience. In drawings of human relations, events and persons, the child expresses others’ attitudes towards themselves and their experiences with significant others (Koppitz 1968, Naglieri et al. 1991).

Obtaining the pain drawings

I collected the drawing data at the hospital as a part of and prior to each child interview and recruited a purposeful sample of 37 children (Paper IV). The original sample consisted of 44 hospitalized children who were inpatients at a university hospital in four wards and participated in the interview study focusing on children’s pain experiences. However, seven children refused to participate in the drawing task. Small children were keen to draw pictures of pain, whereas children approaching their teens were less eager to draw. One child could not draw because of his physiological disability another was recovering from a headache. The other refusals came from those who simply did not want to draw.

The children took 10 minutes on an average to complete the drawing task in the patient room or at the doctor’s office. Twenty-five of the children were accompanied by a mother, father or sibling who was not allowed to intervene. I gave the children a sheet of A4 white paper and a set of six coloured crayons (red, blue, green, black, yellow and brown). I encouraged them to draw a picture that shows a lot of pain and then talk about what they have depicted. Discussion about the children’s drawings helped to build a trustful rapport between the child and the researcher. Moreover the children’s verbal discussion about their drawings enhanced also the content validity of the drawings (Pridmore & Bendelow 1995, Bendelow et al. 1996). Malchiodi (2001) emphasizes that asking about everything in a drawing will mobilize new information and clarify what the child intended to express in the drawing. O’Malley & McNamara (1993) stated also that the assessment of children’s feelings and communication comes from the drawings and from what the children tell about them. After the completion of the drawing, I asked the children to describe their image and recorded this description. It is important for participants to describe their drawing because it necessitates reflection on the drawing and also on the relationship of the drawn image to their pain condition (Guillemin 2004).

In addition to the physiological component of pain, the components of children’s pain experience include also psychological component which refers to the perception of pain sensation through cognitive and emotional elements, and the experiential component, including past experiences, parent-child relationship, the
assignment of the meaning to the experience and culture (Stevens et al. 1987, Schechter et al. 2007). It has long been accepted that pain is a major stressor for children. Moreover, literature describes the emotional reactions of children to illness and hospitalization (e.g. Perrin & Gerrity 1981, Koopman et al. 2004). According to earlier research on children’s conceptions of pain, children who experienced the most intense pain had not reached a developmental stage at which they could find a purpose to pain (Riessland 1983). Because children’s levels of cognitive and artistic development have implications for their ability to symbolize their experiences (Looman 2006) I recruited 22 healthy children as controls (Paper IV). Eight were from a day-care centre (aged from 5 to 6) and 14 from a small local elementary school (aged from 7 to 11). I sought the permission to collect the drawing data in a day-care centre from the manager of the municipal day-care for children and I obtained approval for collecting the drawing data in an elementary school from the individual school principal. The children participated voluntarily. I introduced children’s child-carer and teacher to the approach and they instructed the children as a routine drawing task in their curriculum. The control group children (n=22) were given identical instructions to draw as I had given to the hospitalized group (i.e. Please draw a picture that shows a lot of pain).

Analysis and interpretation of the pain drawings

The starting point in analysing and interpreting the pain drawings was to carefully analyse the collected material. It is beneficial to have a theory, a so called background theory, in a qualitative study, especially when the point of view is deductive. The theory serves as a helping tool for the analysis of the material, and can be used as a reference in the examination (Eskola & Suoranta 1998). In the following sections I describe the analysis of the contents of the pain drawings. Moreover I explain the analysis of cognitive and emotional drawing quality.

Analysing the contents of the pain drawings. In analysing the drawings, my data comprised both the visual images and the children’s verbal descriptions of the drawings. It has been said that a picture is worth a thousand words. Children’s drawings and their accompanying explanations are self-controlled (Clements et al. 2001). The children determined what experiences, emotions or memories they shared with me and it was my responsibility to listen to their interpretation (Driessnack 2005).

I analysed the contents of the drawings using two methods. (Paper IV) The first focused on the expression of pain and the second on the general themes in
children’s drawings. At first, I applied a modification of the classification method of children’s pain drawings by Unruh et al. (1983) and by Jerrett (1985). The eight content categories of pain drawings were as follows: a person or part of a person; action and instruments; physiological representation of pain; location of pain in a body part; emotional expression of pain; abstract representation of pain; actions to manage pain and non-specific content. The children’s descriptions about their drawings served as information for categorizing. One single drawing could contain characteristics of several categories and all alternatives were sorted accordingly. The categorization was based solely on the content commonalities in the children’s pain drawings, without any attempt to interpret the state of mind of the drawer.

To further scrutinize the drawings we (Riitta-Liisa Kortesluoma and Raija-Leena Punamäki) carried out content analysis, as a means of eliciting general themes from the drawings produced, and classified the children’s drawings inductively on the basis of more general themes that did not focus solely on pain expression. We reviewed and recorded content of each drawing and based the analysis solely on the children’s drawings (and not on their descriptions), involving an interpretation of the atmosphere in the scene, and emotions and relational quality of the drawing characteristics. We built the categories through manual coding in order to fully engage with the analytical process and preserve the children’s meanings (Paper IV).

Cognitive drawing quality. Two types of drawing analysis have been developed in the field of screening art productions. One is qualitative, projective analysis and the other is based on a quantitative appraisal (present or absent indicators) in a child’s drawing. The qualitative method considers how well the drawing is composed, including the formal structure, placement and even pressure of the pencil. In addition, Machover (1953) emphasized body parts, including size, shape and position, and erasures. Quantitative analysis was first developed by Goodenough (1926, 1928). Her scoring system was based on the normal developmental levels and general intellectual abilities of a large sample of children’s drawings.

Several reliable and valid drawing tests are available to measure children’s developmental status (Goodenough 1926, Goodenough & Harris 1950, Koppiz 1968, Naglieri 1988, Naglieri et al. 1991, Peterson et al. 1995). Court (1989) suggests that the whole drawings of various subject matters need to be analyzed, rather than just the drawings of a person. That is why we (R-LK and R-LP) took great care in the present study to analyze the whole drawing, including figure presentation. We scored the drawings using Naglieri’s (1988) Draw-a-Person Quantitative Scoring System (DAP: QSS) for cognitive dimensions as most of basic
research on children’s drawing theoretically relies on the results achieved with the paradigm: draw a person (e.g. Knoff & Prout 1985, Frankenburg & Dodds 1990, Van Hutton 1994, Peterson et al. 1995, Clatworthy et al. 1999a, 1999b). At certain ages, children can be expected to include specific items in their human figure drawings and thus developmental assessment can be based on examination of the structure and content of the drawing, in other words the presence or absence of body parts. The number of expected body parts increases with age, thus the developmental level can be described according to the presence of normative items on human figure drawing. Naglieri’s (1988) DAP: QSS is based on the separate evaluation of 12 body parts: head, neck, trunk, arms, fingers, legs, feet, hair, eyes, ears, nose and mouth. Each is scored according to the following criteria: emergence, two-dimensionality, location, details and proportions. For the purpose of this study, the following sum variables were defined: 1. emergence of each of the 12 body parts; 2. two-dimensionality of each body part; and 3. quality of the drawing characterized by factual proportions between body parts, illustrative details and correct location. DAP is based on the rule that each drawing criteria is given a dichotomy score (where 0 = no and 1 = yes), which are summed up. In addition, four bonus scores were possible for perfect drawing dimensions. We calculated the total DAP: QSS ranging between 1 and 60 using SPSS for Windows 14.0. Higher scores indicate a higher level of cognitive performance.

*Emotional drawing quality.* Children’s drawings are commonly used in clinical practice and research to assess children’s emotional status. Machover (1949), Koppitz (1968, 1984), Di Leo (1970, 1973) and Naglieri et al. (1991) have shown that the quality and contents of a drawing reveal the artist’s self-concept, attitudes, anxieties and conflicts. The underlying theory stresses that when a child draws a picture on request from a clinician or researcher, the drawing represents non-verbal communication between the child and the adult. Koppitz, who developed the most commonly used method of evaluating human figure drawings (HDF) for indicators of emotional distress highlights three principles underlying the analysis of them: 1. How a child draws a figure, reflects the child’s own self-concept, 2. The person whom the child draws is the person who is of greatest concern and importance to the child at the time of drawing and 3. What the child is saying in her/his HFD may be twofold: it may be an expression of her/his attitudes and conflicts, or maybe it is a daydream, or both. (Koppitz 1968: 75-77.)

We (R-LK and R-LP) used Naglieri et al.’s (1991) Draw-a-Person: Screening Procedure for Emotional Disturbance (DAP: SPED) to score the emotional quality of children’s drawings. It is a standardized screening test for emotional distur-
bances and based on the work of Koppitz (1968, 1984) who identified 30 emotional indicators (EI) that appear more often in the drawings of children identified with emotional problems than those of normal children. In the Koppitz system the structure of the overall drawing, including shading, symmetry, size, shape, slant, and transparency are evaluated, as well as spontaneously added items or unusual components like teeth, genitals, big hand or clouds. Of the 55 items included in Naglieri et al.’s (1991) DAP: SPED, 20 are among emotional indicators defined by Koppitz. In addition DAP: SPED includes other items such as baseline, figure facing away, gazing left or right and fists. Contrary to Koppitz, who sees some emotional indicators as more pathological than others, Naglieri et al. (1991) do not separate certain items according to their pathology and thus emotional indicator scores by Naglieri et al. (1991) can be used as interval level data in analyses. Moreover, Naglieri et al.’s (1991) DAP: SPED method differs substantially from the Koppitz method because it emphasizes objective scoring and relies on empirical criteria within a normative standardization group.

We (R-LK and R-LP) rated the pain drawings according to the presence or absence of 55 dimensions that depict specific figurative dimensions and pictorial content. The scoring of drawings based on classical indicators of emotional distress and anxiety such as shading, rotated page, small and slanted figures, omission of body parts and contextual information about aggressive or sexual elements. Each indicator received a value of 0 or 1, depending on whether the characteristic item criterion was met. A total DAP: SPED raw score was counted for each child by summing the scores, with higher scores indicating more emotional disturbance. The raw score range is between 0 and 165. Standard T-scores are based on age and gender but they are not related to intelligence levels. T-Score of <55 does not indicate further evaluation, 55–65 indicates further evaluation and when the achieved T-score is >65 further evaluation is strongly indicated. In addition, we (R-LK and R-LP) formed three separate scores according to Goodenough and Harris (1963) indicating severe disturbance of shading, disintegration and disqualification of line drawing.

4.4 Ethical considerations

Any fieldwork raises a number of ethical issues and the development of research with children highlights concerns about a number of ethical aspects arising in the course of a research process. (Beresford 1997, Lindsay 2000, Coad & Lewis 2004)

Earlier, in Section 4.2.1 “Children as Research participants” I discussed the
involvement of children in research from the perspective of children’s rights, as well as informed consent in relation to conducting research with children. These issues are both methodological and ethical. In the next section I consider four ethical issues in relation to conducting research with children: responsibility, power relations, confidentiality, and protection from harm/vulnerability. These ethical issues are not unique to children instead many of them are present also when doing research with adults.

4.4.1 Responsibility

Lindsay’s (2000) discussion about the social responsibility of the researcher is linked with the pursuit of truth in carrying out research. The strong arguments of children’s rights and the personal value positions of researchers threaten to produce conflicting findings with the prevailing orthodoxy. The researcher conducting research involving children is responsible for taking cognitive and emotional development into account and finding a means of communication accessible to the child (Ireland & Holloway 1996, Doorbar 1997, Miller 2000a). Doorbar (1997) notes the traditional misapprehension of children being less articulate and confident than adults because of their age and ability. Ireland & Holloway (1996) emphasise that it is not wise to accept the prescriptive powers of age and stage too literally. Treseder (1997) adds that it is important to honour children’s awareness and maturity when discussing issues of concern to them.

As a researcher I have a responsibility to acknowledge my own value positions and every single issue or account emerging from the research process. This is relevant to Pring’s (2000) reference to the “integrity of research”. Throughout my study I have brought out both my personal value positions and issues and accounts emerging from the research process. In addition, I have tried to report the findings in a value-free way.

4.4.2 Power relations

The balance of power between the researcher and the participants is a controversial issue in any kind of research. In traditional interviewing there is a risk of an inherent asymmetry of power. The unequal power relationship between children and researcher may have a heightened significance. (Hood et al. 1996, Ireland & Holloway 1996, Harden et al. 2000, Kirk 2007.) Adopting power as inherent to research emphasizes the nature of research as a practice that is part of social life,
not an external contemplation of it (Christensen 2004). This means that as a researcher I had to pay attention to broader issues of social and cultural life that may be sensitive to the issues of power. According to Christensen (2004), power as such, has not taken its place in categorical positions, such as adult or child. In my research this meant not viewing children, in principal as different from adults, rather I saw them primarily as fellow human beings.

Balancing the imbalance of power between child participants and an adult researcher requires adopting a role of “naïve curiosity” which presupposes the researcher to being open, honest and understanding in order to avoid short, non-committal answers of children who may feel unsure in the interview situation (Westcott & Littleton 2005). It expects the researcher not to be judgmental, but instead accept the child’s viewpoint as different from that of adults (Butler & Williamson 1994, Coad & Lewis 2004). Kirk (2007) highlights the use of methods which give children the maximum opportunity to provide their views. Moreover, she suggests checking on children’s willingness to participate throughout the interview. I adopted qualitative child interviews with open-ended questions as one of my data collecting methods and pain drawing as another. They are both flexible and give children an opportunity to present their views without restricting their freedom of expression. Furthermore, I reminded every child that they could stop the interview whenever they felt like it. None of the children wanted to do that.

When the balance between the child and the researcher is shifted, children are likely to tell their own stories. It is important to let them speak in their own voices. In this study the participants were the experts in their own lives and experiences of pain, whereas as a researcher, I mainly am the expert in producing definite data within the structures of the chosen research protocol. As a researcher I pondered carefully on the aspects of the research process I needed to control in order to ensure strong findings and what I could leave to the children to decide in order to facilitate their answering in their own terms.

Contextual characteristics, such as the environment in which the research takes place, have an impact on the balance of power. Several studies highlighted the environmental influences in conducting research with children: schools (Pridmore & Bendelow 1995, Horner 2000), early childhood centers/nursery schools (Clark & Moss 2001), hospitals (Ireland & Holloway 1996, Morgan et al. 2002), children’s own home and family settings (Miller 2000b). Each research context brings its own challenges. In adult-led environments (schools, hospitals) children may feel more pressured than in their own places (Punch 2002b).
4.4.3 Confidentiality

According to the ethics guidelines in research, the participants’ right to confidentiality and privacy is absolute (WMA 2000). Confidentiality means that individuals cannot be identified by their responses. Privacy, instead, can be interpreted as a participant’s decision of what information and how much she/he is willing to share. Privacy may also mean secrecy and anonymity (Kankkunen et al. 2002, Helseth & Slettebø 2004). Confidentiality relates to procedures concerning conducting interviews. According to Coad & Lewis (2004), the question of parents’ presence during their child’s interview is much debated. Parents may want but they do not need to know what happens. In my study after getting permission from their child some parents were present during the interview. I guaranteed confidentiality and anonymity in the written documentation by replacing the children’s names with pseudonyms, when transcribing the interviews from the tapes. The interview data were not available to anybody other than me.

Confidentiality is also an issue in the dissemination of research findings. The protection of anonymity might be more difficult to guarantee in the possible subsequent use of children’s drawings in published material than is the issue with the written interview data (Backett-Milburn & McKie 1999).

4.4.4 Protection from harm/vulnerability

Despite the changing view of children as active members of society and being research participants in their own right, they are still seen as vulnerable, incompetent and in need of protection because of their cognitive and developmental abilities (Christensen 1998, Neill 2005). Protection from harm and vulnerability means that participating does not cause any physiological, emotional, social harm and discomfort to the study participants (Kankkunen et al. 2002).

The children participating in this research were vulnerable because of being children, being ill and hospitalized and in a strange environment. During the research process, I always considered the children’s interest first. For example, I did not conduct an interview when any of the children were experiencing pain. In this study I especially bore in mind, when gathering the research data, that children feel stress more easily than adults in research situations. The children might have been exposed to potential harm when they possibly experienced emotional discomfort while talking about their pain. For this reason, I wrote in the field notes additional communication related to the interview situation and observations I had.
made of the child during the interview. I described the atmosphere of the interview briefly, even though I did not observe any discomfort or anxiety. Instead the children were very keen on telling their stories about their pain.

4.5 Summary of the background influences and methodological choices of the study

Pain is a complex phenomenon and an inherently subjective experience with many emotions. It is extremely demanding as a research topic, particularly when children’s experiences of pain are the case. Issues that have touched a person emotionally are, in actual fact, studied when investigating experiences.

Catching children’s pain experiences necessitates a multifaceted approach, in which effective communication is essential in order to attain precise and extensive data. I understand a child as a subject of his/her own activities, as a doer and commentator actively taking part in the dialogue and the research process. I, also, as a researcher act as a subject in this process. I turn to children’s verbal and visual expressions and search for realities expressed by them. In that case I operate with concepts and I try to see and understand the phenomenon under study. Consequently, the attained information is based on both inter subjective concepts and expressions as well as on the children’s subjective experiences which I externalize by description. (see Töttö 1982: 1-6, Parse et al. 1985: 15-68, Reilly 1989.) In figure 7. I summarise the theoretical background influences and methodological choices of the study.
Fig. 7. The theoretical background influences and methodological choices of the study.
5 Findings

In this study I examined qualitative child interviewing as a research method and children’s pain experiences in hospital setting as described and drawn by the children themselves. Further, the aim was to improve pain assessment and management in hospitalized children by approaching the question from the children’s point of view and from their needs. In the next sections I will describe the study findings based on the original articles, including: qualitative child interviewing as a research method (Paper I), the sources and causes of hospitalized children’s pain experiences (Paper II), hospitalized children’s pain descriptions and their views of the purpose of pain (Paper III), hospitalized children drawing their pain (Paper IV) and pain alleviation methods used by children and their expectations of other’s help (Paper V).

5.1 Qualitative child interviewing as a research method (Paper I)

In this section I highlight the main points of qualitative child interviewing as a method. I encapsulate in detail the phases of qualitative child interviewing and include some practical solutions to use during interviews (Figure 8, on page 68).

Preparing for the interview. Discussions of child interviewing refer to the a priori assumptions that influence the orientation of the research. These approaches are mainly based on notions of children and childhood and the possibility of an adult understanding of children and their experiences. A basic requirement for child interviews is that the researcher is interested in the experiences and stories of children. The interview process should be consistent with the research paradigm employed. The ways to use interviewing in the particular methodology should be considered, and the process should originate from the pre-insights or assumptions the researcher has about children and childhood. However, interviewing always has a common core irrespective of these pre-insights.

An interview is a very important event in a child’s life. It is evident that the subjective nature, knowledge and verbal abilities of children, as well as the narrative competence of children need to be taken into account when assessing an interview from a scientific point of view. The influences affecting interviews with adults are relevant to children, but there are additional factors too. Children are not miniature adults. For all sorts of reasons, young children are vulnerable, and more context dependent and context vulnerable than older children and adults. To handle
vulnerability, researchers require special skills in understanding the nature of childhood and sensitivity to differences.

Before the child’s enrolment in the study, the gatekeeper’s permission must be obtained first. After obtaining the gatekeeper’s permission, assent from the child can be sought. Children should be given a full explanation of what the research and interview entail, as well as an opportunity to reflect on these before making a decision to participate. It should be kept in mind that a child’s refusal overrides the gatekeeper’s permission.

**Introductory Phase.** The feasibility of qualitative child interviewing as a method of data collection depends especially on the interviewers’ ability to gain the children’s confidence and to get involved in the interaction between themselves and the children. Apart from establishing rapport, the success of the interview also depends on how well researchers can maintain the interaction and co-operate with children. Engaging the child begins through creating a secure and safe atmosphere. This sets the tone for the rest of the interview.

The interview is a fact-finding process. When the aim is to collect reliable data from children, special attention should be given to the individuality of the children and their particular developmental stage, regardless of their chronological age.

It is advisable to introduce the interview rules at this point. They give the child a sense of what to expect. The younger the child the more concrete the concepts used to explain the purpose of the research. Using concepts of abstract, altruistic rewards in the future or from the utilitarian points of view, such as increasing scientific knowledge should be avoided. In this phase it is time to motivate the child, give an assurance that all answers are acceptable and give permission to withdraw at any time.

**Investigative phase.** In this phase the actual information is gathered. The interviewer should always keep in mind the focus of the interview. Pilot interviews add to the reliability and validity of the actual interviews. They make it possible to learn to ask the kinds of questions that are suitable in terms of the trustworthiness of the data. The characteristics of qualitative interviewing in data collection must also be recognized. Interview schedules should be well-planned to ensure that open-ended questions are used maximally. When interpreting children’s answers, one should not concentrate on the developmental norms defined for a certain age, but rather modify the interviewing techniques according to the individual development of each child. A child is sensitive to the stimuli given by the interviewer, and these stimuli may orientate the child’s answers in a certain direction. On the other
hand, providing different stimuli is a good way of making sure that the answers are consistent.

A child may understand the interview situation as school-like, akin to teacher-student relationship when the importance of giving rights answers to the questions is emphasized. Children (even at the age of eight) imagine that adults know everything and an interviewer knows the right answers beforehand. In this case a child’s answers reflect more the items that she/he thinks an interviewer wants to hear, instead of how these items really appear in a child’s life. Numerous “I don’t know” or “I don’t remember” answers may demonstrate the effect of imbalance in the power relationship.

There are many contextual factors in interviewing that affect the act of answering. The tone and atmosphere of the interview depend on the way the interaction between child and researcher proceeds. The situation may confuse both partners. At the beginning of qualitative interviews, when evoking children’s experiences, it is good practice to accept their answers without any criticism whatsoever. If the answer is unsatisfactory, the interviewer can resume the question later on, or in another way. Children’s feelings can usually be approached through their actual experiences. This makes a discussion-type interview possible, which, in turn, makes the whole interview easier to conduct. Long interviews should be avoided because of children’s limited ability to concentrate.

**Concluding the interview.** It is a good practice to offer the children the opportunity to receive feedback about their participation and give all the children a small token reward for participating. Because participating in research is not a part of children’s routine activities this exchange reflects respect for the children’s time and efforts.
Fig. 8. Guidelines for the process of qualitative child interviewing.

**Preparing for the interview**
- Examine your a priori assumptions about children and childhood
- Understand the development of narrative competence of children
- Get acquainted with the methods of child interviewing and learn to listen
- Consider an adult's chances for understanding children and their experiences
- Furnish yourself with a tape recorder and microphone (it motivates the child)

**Asking consent/assent**
- At first turn to gatekeepers
- Ask the child's assent
- Appointing the time of the interview

**Selecting the setting in which to conduct the interview**
- Familiarize yourself with the interview setting before the actual interview
- Choose a quiet and private place

**Introductory phase**
- Build up a trustful rapport e.g. by playing with the child, or drawing and discussion about the drawing
- Appraise the overall developmental age of the children
- Give information
- Explain the aim and the structure of the interview, the expectations and role of the interviewee at each child's comprehension level
- Assure there are no right of wrong answers
- Motivate the child
- Give the child permission to stop the interview at any time

**Investigative phase**
- Conduct pilot interviews
- Keep in mind the focus of the interview
- Modify your language according to the child's developmental stage
- Formulating questions:
  - Start with general open-ended questions to concrete facts, move slowly to more abstract topics
  - Formulate the questions in such a way that they do not generate only a negative or a positive answer
  - Formulate questions positively, so that there is no indication whatsoever of any particular answer being better than others
  - Provide different stimuli for the production of answers
  - Use words denoting action it makes easier for children to answer

**Concluding the interview**
- Let the child listen to the tape-recorded interview
- Thank the child and give a small reward
- Make notes about how the interview went and feelings about the interview and its atmosphere
5.2 The sources and causes of hospitalized children’s pain experiences (Paper II)

Pain turned out to be a frequent and significant factor in children’s illnesses and treatments. All the participating children had experienced pain in more than one situation. They were able to remember different pain experiences and to share these experiences with the researcher. The pain experience of the participating children came from four main sources: 1. pain caused by a diagnosed basic illness, 2. pain caused by medical and diagnostic procedures and basic nursing, 3. pain caused by accidents and 4. inexplicable pain not caused by a particular illness or injury and imaginary pain. Table 4 gathers together the sources and causes of pain experiences of the interviewed children.

Table 4. The sources and causes of pain experiences of the interviewed children.

<table>
<thead>
<tr>
<th>Main category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain as a symptom of a diagnosed illness</td>
<td>Inflammations, cancer, renal and urinary diseases, gastrointestinal diseases</td>
</tr>
<tr>
<td>Pain caused by medical or diagnostic procedures and basic nursing</td>
<td>Postoperative pain, vena punctures, insertion of intravenous lines, procedures on bone marrow and muscles: injections, punctures and needle-ENMG</td>
</tr>
<tr>
<td>Pain caused by accidents</td>
<td>Falls, blows, burns</td>
</tr>
<tr>
<td>Inexplicable pain not caused by a particular illness or injury and imaginary pain</td>
<td>Recurrent pains associated with childhood, such as headaches, stomach aches, limb pains</td>
</tr>
</tbody>
</table>

The children ranked their experiences of pain according to intensity, and assessed this intensity spontaneously by such reactions as crying during the experience. Crying due to pain or inability to sleep because of it, were considered as consequences of intense pain. Pain and distress prevented sleeping. The children used autonomic symptoms caused by pain in order to measure its intensity, such as sweating and vomiting. A sensation of internal bleeding also increased the intensity of pain.

Pain as a symptom of a diagnosed basic illness. While in hospital, the children suffered many pains caused by common paediatric diseases and children’s chronic diseases (Table 4). Chronic pain all over the body was caused by the symptoms of these diseases, by staying in all the time or was a side-effect of the diseases. Bed rest because of the basic illness caused pain which prevented normal physiological functions (e.g. eating and sometimes even breathing). Tumours induced pain in the body part where the tumour was located and caused a general ill feeling. Children
with chronic pain were so used to being in pain that they considered it a normal part of their life.

**Pain caused by medical and diagnostic procedures and basic nursing.** The children had experienced different medical and diagnostic procedures (Table 4 on page 69) and basic nursing, during which (and due to which) they suffered pain. The children had undergone different surgical procedures. They remembered well the postoperative pain in the operated body part. It was regarded as one of the most intense pains they ever had. An uncomfortable position and tension in the operated body part increased the intensity of postoperative pain. Lifting and moving the children caused pain in the operated body part.

Despite experiencing post-operative pain, the children were happy about their problem being repaired. The appearance of the operated body part affected the interpretation of the quality and intensity of the pain. The more unpleasant the outlook of the operated body part, the more severe the post-operative pain was considered to be. Pain prevented children’s normal routines and caused fear when beginning to move about after surgery. Wound pain and too-tight bandages caused such intense pain that it woke children up. Sensitivity when being touched was typical of surgical wounds.

All the children had experienced pain caused by repeated diagnostic procedures, medication and treatments (Table 4). Procedures involving needles caused extreme pain. In general, all injections hurt and were scary. The location for the injection affected the intensity of the experienced pain. The intensity of pain caused by injections was connected with the child’s knowledge and experience of drawing blood. Blood tests were as frightening as seeing blood in general. The assumptions the children had of pain and blood affected the intensity of the pain experienced during these invasive procedures. Anticipation of pain led to an exaggerated pain experience, fear (e.g. of bleeding to death) and resistance to the procedure. Seeing the instruments to be used in the procedure increased the intensity of pain. Procedures in the bone marrow did not hurt as much, as they were done under anaesthesia. However, almost all of the children had headaches after bone marrow punctures and procedures done on the spinal cord.

One of the most intense pains was experienced during and following infusions of medication or blood products. The drop rate of the medication and the size of the blood vessel were relative to the intensity of the pain experienced. The quicker the drop rate and the smaller the vessel, the more pain the infusion caused. The leakage of infusion liquid into muscle and removal of the infusion needle from the vein hurt. Medication infusion caused a loss of appetite and nausea, which was
also counted as pain. The side effects of medication e.g. becoming sensitive to medication and blood products caused a sensation described as pain.

Some individual procedures of basic nursing turned out to be painful. The removal of stitches and blood oozing from the holes of the stitches increased the intensity of pain. The extent of experienced pain caused physical symptoms such as sweating and nervousness, even though the procedure had been explained beforehand.

Pain caused by accidents. On admission into hospital, some of the children had acute pain caused by accidents (Table 4) that had occurred in everyday activities. Fractures and dislocations of bones and vertebrae were classified as one of the most intense pains experienced. Stigma produced by an illness or injury stimulated the child’s pain experience and affected the interpretation of pain and its intensity and intensified the degree of suffering. Bone fractures and pain caused by falling caused anticipation of pain e.g. traumatic external factors causing pain in the operated body part, which was already hurting.

Inexplicable pain. Some of the children had suffered from different and frequent pain in childhood which could not be linked to any recognizable illness or injury, but which were not clearly psychogenic either. These were inexplicable, recurrent pains, such as headaches and stomach aches. The pain as a symptom was aggravated apparently by external factors. The pain was not excruciating, although it was some of the most intense ever experienced. One of these was pain in their lower extremities that could be recognized easily as growing pain.

Pain caused by aggressive actions of other people. The burden of pain of the interviewed children was increased by the aggressive behaviour of others. One of the most intense pains was the physical pain caused by being hit. In addition to physical pain, hitting also caused emotional suffering. Moreover, verbal abuse was felt as pain.

When it does not hurt. In addition to their most intense pain experiences, the children named situations in which they had not had intense pain or had not experienced any pain at all. The fact that, for some children, the situations of no pain were the same as those where the other children had experienced the most intense pain, demonstrates the subjectivity of the pain experience. The child’s basic illness, medication and previous experiences of pain and being hospitalized were implicit in these descriptions. The children constantly compared their different experiences of pain. It was evident that something that did not feel really bad, felt tolerable in view of the child’s overall situation.
In cases of pain caused by repeated diagnostic procedures and treatments, experiences varied between extreme pain and only a mild pain or none at all. Generally, injections were painful, but strong pain medication for basic illness or injury reduced this pain. One positive aspect to having injections was their short duration.

5.3 Hospitalized children’s pain descriptions and views of the purpose of pain (Paper III)

All the children had experienced pain on several occasions (see Table 4 on page 69). Descriptions of pain focused on situations and pain-provoking events in hospital closely preceding the interviews.

5.3.1 The children’s descriptions of their pain

Different causes and sources induce different pains which feel different. Data analysis resulted in the multidimensional nature of pain including three main themes of the ways children described their pain. They used a common vocabulary of physical, psychic and evaluative words to describe their pain experience.

*Multidimensional pain.* The children regarded pain as a multidimensional phenomenon. Children’s descriptions of pain introduced the physical dimensions of pain, such as location, quality, thermal and autonomic responses and weakness induced by pain. The expressions indicated counting on information produced by senses, switching to a more abstract way of thinking and ability to integrate the experience. Most of the children described their pain experiences easily by using numerous adjectives, verbs and adverbs and preferred more active expressions. The quality of the pain was specified e.g. as pounding, stabbing, splitting and throbbing. There were also some cases of personification (= thinking of a thing as having life).

The psychological dimension of pain included emotions, such as restlessness, fear, and cry caused by pain. Regardless of personal experiences, pain was always confusing and strange. The psychological aspects of pain became evident in descriptions using general terms such as terrible, disgusting and annoying. Increasing evidence of a linkage between pain and mood became apparent e.g. when pointing out the feeling of mental isolation. Pain also caused concern about the integrity and physical health of the body.
Generated evaluative descriptions expressed duration and statements about the intensity of pain. The ability to classify and quantify became evident in descriptions of the duration as well as the location and intensity of pain. In general, the expressions became more introspective and abstract with advancing age (Table 5).

*Paraphrases.* In the simplest descriptions pain was characterized as aching and hurting. Feeling painful, having pain, and causing pain were paraphrases used by the children (paraphrase = clarification or euphemism of a word, an expression or a text presented by other words, or a definition of value based on alternative manifestations).

*Generalization.* Regardless of its location in the body, pain felt like the most disgusting emotional experience described by the negative consequences of pain, such as immobilization and restriction of activities. Generalization of pain found its expressions in descriptions of holistic discomfort (Table 5).

*Intensifiers and metaphors.* Descriptions of pain involved also intensifiers such as ‘very exhausting’ or ‘very horrible’. Numerous metaphors coloured the descriptions to make the pain visible. Metaphor is a figure of speech containing an implied comparison, in which a word or phrase ordinarily or primarily used of one thing is applied to another (Webster’s New World Dictionary 1994). Metaphors show how two things that are not alike in most ways, but are similar in one important way. They are a way to describe something. Table 5 gathers together the expressions of the children when describing their pain.
Table 5. The expressions of the children when describing their pain (The quotes have been directly translated from Finnish into English).

<table>
<thead>
<tr>
<th>Physical pain</th>
<th>Psychic pain</th>
<th>Evaluative expressions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Location</strong></td>
<td><strong>Restlessness</strong></td>
<td><strong>Duration</strong></td>
</tr>
<tr>
<td>- The pain was radiating...</td>
<td>- Can't be at peace</td>
<td>- Every time</td>
</tr>
<tr>
<td>- Bad feeling in my whole body</td>
<td>- It was tense</td>
<td>- Doesn't always feel as bad</td>
</tr>
<tr>
<td></td>
<td>- Restless feeling, don't know what to do</td>
<td>- Occasionally it feels very bad</td>
</tr>
<tr>
<td></td>
<td>- Annoying</td>
<td>- Doesn't hurt as much every time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Stabbed terribly all the time</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Sometimes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Never-ending, you can't do anything to it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Now and again</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Continuous</td>
</tr>
<tr>
<td><strong>Quality</strong></td>
<td><strong>Affective</strong></td>
<td><strong>Intensity</strong></td>
</tr>
<tr>
<td>- Throb</td>
<td>- Strange</td>
<td>- Irrationally</td>
</tr>
<tr>
<td>- Pinches</td>
<td>- Looks bad</td>
<td>- It is not always alike</td>
</tr>
<tr>
<td>- Stabbing</td>
<td>- All pains are as bad</td>
<td>- Common, it hurts ordinarily</td>
</tr>
<tr>
<td>- Sticks</td>
<td>- Miserable, miserably</td>
<td>- A bit, a little</td>
</tr>
<tr>
<td>- Feels like pricking</td>
<td>- Feels disgusting</td>
<td>- Deady</td>
</tr>
<tr>
<td>- Grabbing</td>
<td>- Not nice</td>
<td>- Terribly</td>
</tr>
<tr>
<td>- Press, a little like pressing</td>
<td>- Doesn't feel comfy, not at all comfy</td>
<td>- Very horrible pain</td>
</tr>
<tr>
<td>- Not a sharp pain like a stab but it feels somehow different</td>
<td>- Not so very exhausting</td>
<td>- Quite bad</td>
</tr>
<tr>
<td>- Squeezes</td>
<td>- Very sad</td>
<td>- Slightly</td>
</tr>
<tr>
<td>- Itches</td>
<td>- Hateful</td>
<td>- Sadly/not sadly, feels like intense pain</td>
</tr>
<tr>
<td>- Splitting</td>
<td>- Odd</td>
<td>- Quietly</td>
</tr>
<tr>
<td>- Pulls, banging</td>
<td>- Awkward</td>
<td>- Dreadfully, horribly bad</td>
</tr>
<tr>
<td>- Tugging</td>
<td>- Apprehensive</td>
<td>- Hatefully</td>
</tr>
<tr>
<td>- Pounding</td>
<td>- Feels (very, quite, a little, fairly) bad</td>
<td>- Not so very hard</td>
</tr>
<tr>
<td>- Consistent</td>
<td>- Distressing</td>
<td>- So hard that I had to scream</td>
</tr>
<tr>
<td>- Rough</td>
<td>- Feels bad</td>
<td>- Just feels</td>
</tr>
<tr>
<td>- Tender, sore, sensitive</td>
<td>- Feels nothing, it doesn't feel like anything special</td>
<td></td>
</tr>
<tr>
<td><strong>Thermal</strong></td>
<td><strong>Cry</strong></td>
<td><strong>Paraphrases</strong></td>
</tr>
<tr>
<td>- Smarting</td>
<td>- It hurt so badly that, I started to cry (bad mood)</td>
<td>- Feeling painful</td>
</tr>
<tr>
<td>- Stinging</td>
<td>- It makes me cry and I feel like screaming like a lion</td>
<td>- Upsetting</td>
</tr>
<tr>
<td>- Burning</td>
<td>- So hard that it would make you cry</td>
<td>- Causing pain</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Aching</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Hurting</td>
</tr>
</tbody>
</table>
Table 5. continued

<table>
<thead>
<tr>
<th>Autonomic responses</th>
<th>Fear</th>
<th>Metaphors</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Makes me nauseous</td>
<td>- Sad</td>
<td>- As if my ears were blocked</td>
</tr>
<tr>
<td>- Sickening</td>
<td>- Anxious</td>
<td>- Hurts so much that it feels like my bones would fracture</td>
</tr>
<tr>
<td>- Dizzy</td>
<td>- Shivery</td>
<td>- Like someone would tear my skin off or try to take pieces out of it</td>
</tr>
<tr>
<td>- Rumble</td>
<td>- Awful</td>
<td>- Like my legs were breathing and stiff</td>
</tr>
<tr>
<td>- Whirled in my stomach</td>
<td>- Terrible</td>
<td>- Like every bone in my body was broken</td>
</tr>
<tr>
<td>- Giddy</td>
<td>- Frightening</td>
<td>- Like someone digging with a scoop in my stomach</td>
</tr>
<tr>
<td>- Makes me sweat</td>
<td>- Fearful</td>
<td>- It hurt like a midget or bee sting</td>
</tr>
</tbody>
</table>

Weakness
- It hurt so much that I could not possibly stay
- One can't and one doesn't manage to do anything
- It feels that occasionally you can't even breathe
- You can't even move
- I couldn't sleep
- You can't eat, the food doesn't taste of anything
5.3.2 The purpose of pain

Life-protecting phenomenon. The biological meaning of pain was understood as a life-protecting phenomenon. The nature of pain was illustrated as a normal function of senses, just as seeing and hearing. The task of the tactile sense is to feel pain and cause a warning signal of tissue damage. This, in turn, leads to activities that prevent further tissue damage. The purpose of pain in the normal psychological development of a man was explained by learning about pain. The learned fear of pain leads to avoiding pain and pain-provoking situations.

Personal benefit. The psychosocial meaning of pain was very clear: in the role of a patient, the child could get attention as well as the material and emotional care which the child might otherwise not receive. Pain was also an escape. The role of patient relieves of the usual responsibilities and daily routines at school and at home and thereby reduced stress.

Diagnostic aid/symptom of an illness. Pain was identified as a diagnostic aid. The purpose of pain and pain-provoking procedures was understood as making children better indirectly. Pain was a symptom and a substantial part of illnesses requiring medical help.

Future orientation. Future-orientation was evident when the purpose of pain was identified as a phenomenon that widens the perspective and prepares for life. Characterizations of the experience of pain emphasised the encouragement of mental development.

Societal implications. Things that are sensed, perceived and created mentally are combined in the experience. This became evident when speaking about the purpose of pain. Deliberation upon pain even from the linguistic and societal points of view seemed to give perspective to the children’s thoughts and issues.

5.4 Hospitalized children drawing their pain (Paper IV)

We (R-LK and R-LP) compared the pain drawings of the hospitalized children and their healthy controls, and analysed the impact of the child’s illness diagnosis on the contents, cognitive quality and emotional disturbances of the drawings in the hospitalized group. In these two sections below I describe how children’s illness and hospitalization are associated with: 1. the contents and 2. cognitive and emotional characteristics of their drawings about their pain experiences. The results are based on paper IV, Kortesluoma et al. 2008a).
5.4.1 Contents of the pain drawings

The distribution of the content categories in the hospitalized and healthy control groups are shown in Figure 9 (see also Table 3, Paper IV). Almost all of the children in both groups represented a person or a part of a person when drawing pain. One-third (32.4%) of the hospitalized children and 45.4 percent of their healthy controls placed pain in a specific part of the human body (Figure 10, on page 78 and 11, on page 79). The main difference between the groups was in children drawing medical actions versus human relations. The hospitalized children’s drawings of pain involved predominantly (54%) actions, procedures and instruments inflicting pain (Figure 12, on page 79), whereas only 18.2 % of the control group children drew these themes. One-third (31.8%) of the healthy children drew pain through the expression of emotions: their art work showed feelings of being sad, in pain (crying) and seeking consolation (Figure 13, on page 80). Only 10.8% of the drawings of hospitalized children involved an emotional expression of pain. Almost one-third (27.3%) of the healthy children’s drawings, compared to only 8.1% of the hospitalized children’s drawings illustrated actions to manage pain (Figure 14, on page 80). None of the children represented the presumed physiological presentation of pain.

![Fig. 9. Distribution of the contents of the pain expression in the drawings of hospitalized and control group children.](image)

Similar group differences emerged when comparing the general themes of the children’s drawing of pain. The results are shown in Table 6. The hospitalized children drew hospital settings and medical procedures more often than their healthy controls (Figures 15 and 16, on page 81). On the contrary, the children in the control
group more often drew themselves in consoling and joyful situations, and their pain pictures more often included human relations, in the form of family interactions and peer relations (Figure 17 on page 82).

Table 6. Differences in general theme contents among hospitalized children and their healthy control group (Means, Standard Deviations and Statistical values).

<table>
<thead>
<tr>
<th>General theme content</th>
<th>Illness &amp; hospitalization group</th>
<th>Healthy control group</th>
<th>F-values*</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital setting</td>
<td>0.65 (.08)</td>
<td>0.22 (.11)</td>
<td>10.11**</td>
<td>.14</td>
</tr>
<tr>
<td>Medical procedures</td>
<td>0.73 (.07)</td>
<td>0.17 (.10)</td>
<td>20.77****</td>
<td>.26</td>
</tr>
<tr>
<td>Threat and danger</td>
<td>0.32 (.08)</td>
<td>0.44 (.12)</td>
<td>0.39</td>
<td>.01</td>
</tr>
<tr>
<td>Condolence &amp; joy</td>
<td>0.68 (.09)</td>
<td>1.17 (.13)</td>
<td>9.32**</td>
<td>.12</td>
</tr>
<tr>
<td>Human relationship</td>
<td>0.30 (.11)</td>
<td>0.83 (.15)</td>
<td>8.30**</td>
<td>.11</td>
</tr>
<tr>
<td>Absence of adult</td>
<td>0.32 (.08)</td>
<td>0.50 (.16)</td>
<td>1.57</td>
<td>.02</td>
</tr>
<tr>
<td>Pet or other animal</td>
<td>0.05 (.04)</td>
<td>0.06 (.05)</td>
<td>0.01</td>
<td>.00</td>
</tr>
<tr>
<td>Child alone</td>
<td>0.76 (.07)</td>
<td>0.89 (.09)</td>
<td>1.30</td>
<td>.02</td>
</tr>
</tbody>
</table>

*df = (1, 54)
*p < .05, **p < .01, *** p < .001, **** p < .0001

Fig. 10. “Well, I lie in plaster there.” (Girl, 10 yrs old, from a hospital group).
Fig. 11. “My drawing is a terrible mess, but so is my pain too.” (Girl, 10 yrs old, from a hospital group).

Fig. 12. “This is the doctor and this is me and then that shot into my back.” (Boy, 10 yrs old, from a hospital group.)
Fig. 13. Drawn by a boy, 8 yrs old, from a healthy group.

Fig. 14. Drawn by a girl, 9 yrs old, from healthy group.
Fig. 15. “There are,... such drops go into my arm.” (Girl, 8 yrs old, from a hospital group)

Fig. 16. “My scar hurts and the nurse brings me pain medicine.” (Girl 7 yrs old, from a hospital group)
Fig. 17. Drawn by a boy, 11 yrs old, from a healthy group.

Fig. 18. Drawn by a girl, 9 yrs old, from a healthy group.
5.4.2 Cognitive and emotional qualities of pain drawings

One-way analyses of variance (ANOVAs) were performed to compare the cognitive and emotional dimensions of drawings between the hospitalized children and their healthy controls. The dependent variables were the total DAP: QSS score, two dimensionality, correct proportions and adequate details of human drawing, indicating quality of cognitive performance and total DAP: SPED, and shading and disintegration indicating emotional disturbance.

The results are shown in Table 7. III and hospitalized children differed from their healthy controls in all cognitive indicators, and in one indicator of emotional disturbance. The cognitive level of the drawings in the healthy control group was generally higher than that of the hospitalized children, whether indicated by the total DAP score or specified by figurative characteristics of two-dimensionality and right proportions, and involvement of details such as jewellery, buttons or decorations. The total DAP: QSS was almost twice as high among the healthy controls as the hospitalized ill children. Concerning the emotional aspects of pain drawings, unexpectedly the healthy control children showed more emotional disturbance, indicated by shading and disintegration of drawing, than the hospitalized children. (Figure 17 and 18, on page 82)

Table 7. Differences in cognitive quality and emotional disturbance of children’s pain drawings among hospitalized children and the healthy control group (Means, Standard Deviations and Statistical values).

<table>
<thead>
<tr>
<th>Drawing qualities</th>
<th>Illness &amp; hospitalization group</th>
<th>Healthy control group</th>
<th>F-values*</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive quality</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total DAP</td>
<td>15.42 2.16</td>
<td>31.45 2.84</td>
<td>20.12****</td>
<td>.26</td>
</tr>
<tr>
<td>Two dimensionality</td>
<td>2.03   .38</td>
<td>5.59   .50</td>
<td>32.19****</td>
<td>.36</td>
</tr>
<tr>
<td>Right proportions</td>
<td>2.55   .60</td>
<td>4.91   .77</td>
<td>5.83*</td>
<td>.10</td>
</tr>
<tr>
<td>Adequate details</td>
<td>1.47   .43</td>
<td>4.60   .58</td>
<td>18.57****</td>
<td>.26</td>
</tr>
<tr>
<td>Emotional disturbance</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total DAP:SPED</td>
<td>23.65 1.04</td>
<td>26.23 1.35</td>
<td>2.27</td>
<td>.04</td>
</tr>
<tr>
<td>Shading &amp; disintegration</td>
<td>18.30   .98</td>
<td>21.50 1.27</td>
<td>3.99*</td>
<td>.07</td>
</tr>
</tbody>
</table>

*df = (1, 54)  
*p < .05, **p < .01, ***p < .001, ****p < .0001

The impact of the child’s illness diagnosis on the content, cognitive and emotional qualities of the drawings were analysed by using one-way ANOVAs in the hospitalized children’s group. The results show that children diagnosed with locomotive
illness showed a higher level of emotional disturbance in their drawings, compared to children with tumours, internal diseases and accidents (F (3,34) = 3.00, p < .04). The children’s diagnosis did not impact on the cognitive level of their drawing or drawing content.

5.5 Pain alleviation methods used by children and their expectations of other people’s help (Paper V)

In this section I describe the interventions young children use themselves, and expect from others, when managing the pain experienced by them during hospitalization. Identifying the children’s preferences and expectations helps care-providers to intervene appropriately. Knowledge of children’s views and dissemination of their suggestions on pain management paves the way towards better pain management in children and leads to child-originated, and more effective clinical practice (Kortesluoma et al. 2003, 2008b).

The children produced a variety of meaningful statements dealing with their self-help strategies for pain, professional and other helpers, their distrust of pain management, as well as other generated sources of pain relief.

5.5.1 Children’s self-help strategies for pain

The children were very experienced in using diverse self-help strategies during pain episodes. As shown in Figure 19, they used both sensory/physical and cognitive/behavioural actions.

*Sensory/physical actions.* In spite of the thoughts of bed rest lessening the children’s options in pain relief, the children counted on self-help and were very spontaneous in using generally safe sensory/physical interventions. They discovered these actions by themselves but also were introduced to these by the nurses. Particularly, interventions like massage, caressing, deep breathing, moving or changing the body posture, application of heat or cold, resting and relaxation, immobilisation or exercise, eating or drinking, loosening tight clothes and defaecation gave the children a sense of control over the pain sensation and their own behaviour.
Fig. 19. Children’s self-help strategies for pain.
Cognitive/behavioural actions. The cognitive/behavioural actions change either the children’s own behaviour or the behaviour of others who interact with them. They lessen the behaviour which can increase pain and discomfort and at the same time increase behaviour which reduces pain. The children actively sought preparatory information and provided information on their pain sensation as well. They aimed at a conscious processing of the pain experience by positive self-instruction, positive self talk, attention diversion and thought-stopping. The children tried to get some decisional control over pain provoking procedures by offering their own choices of action. The children tried to make the pain more tolerable by composing themselves or playing down the pain provoking situation. In fear of pain they tried to avoid pain and refuse diagnostic and nursing interventions they knew or supposed to be pain intensive. A few children relied on aggression or revenge/self-defence when pain was induced by someone’s unskilful or aggressive activities.

5.5.2 Expectations of professional help

The children had made very detailed observations of professional helpers and their possibilities in relieving their pain. They expected competence, empathy and time for alleviating their pains.

Competence. The nature of the pain and pain episode directed the child to select helpers. The long-term ill children counted on professional help provided by the medical and nursing personnel. Help, provided by medical doctors, rested on their professional expertise and was based on appropriate instruments. The children made demands on health care professionals’ behaviour and expected competence.

Empathy. The children did not trust the nurses’ help because they are not close enough to the child in order to provide individualized help as needed. Theoretical explanations from nurses who think that they understand the child’s experience and try to explain things from their own perspective do not help. On the other hand, the children appreciated the nurses who can empathize.

Time. The children felt that they had to push for pain relief. They stated that the nurses relieved their pain only in a case of emergency. They found that nurses were always busy and needed more time to help. In those cases, the children had to discover the means of handling their pain for themselves.
5.5.3 Significant others as helpers

The children identified other possible help-providers as well. Some of the children found helpers among their family members. Some of the participants greatly doubted the potential of their significant others to relieve distress during a pain episode. However, most of all the children were not as selective in finding help-providers. In addition to accepting help from parents, siblings, grandparents, relatives and friends, they were also ready to receive help from strangers in an emergency.

5.5.4 Nothing can help

When experiencing intense pain some of the children were very pessimistic in relation to help providers and pain management. They felt that nothing and no-one can help that kind of pain. Such pain can last for a long time and nothing was done. Moreover, some of the children were very fatalistic about pain relief in the case of procedure related pain.

5.5.5 Other generated sources of pain relief

Most of the children reported several other sources of pain relief, generated by others which included hospital, medicine, emotional support, help in daily activities and modifying the environment.

Hospital. The younger children named some passive external treatment-related factors the parents had adopted when acute pain caught the child by surprise. For them, the only option was to go to hospital or to the doctor's when in pain. The children, whose basic illness demanded contact with a medical doctor even in the appearance of the smallest health problems, limited the possibilities of the parents to help in informing the child's condition to the caring unit and taking the child to the hospital.

Medicine. The children relied on medication. They were convinced that nothing else but medication could help in pain and they could not name any other helping factors. The children were able to and even insisted on getting pain killers. They could list some pain killers by brand name. According to them medication alleviated pain taken in any form (IV, tablets, injection), but in the case of very intense pain medication had to be infused.

Emotional support. The presence of family members during pain episodes and pain provoking procedures puts the child's mind at rest. The significant others can
hug the child, hold his/her hand, or nestle and comfort the child and thereby offer emotional support. According to the children some nurses might have the same effect.

*Helping in daily activities.* The children recognized that parents cannot help during severe pain in hospital instead they can assist the child in daily activities and enable mobilisation.

*Modifying the environment.* Only one child reported experiences of modifying the nursing environment for pain relief.
6 Discussion

In the next sections I discuss the issues affecting the trustworthiness of the study and identify the limitations of the study. I also highlight the most important findings of the study. Further, I considered the ethical aspects of my study in earlier sections (4.2.1 Children as research participants and 4.5 Ethical considerations). Here I focus my attention on the ethical aspects of my study that I have not discussed earlier. Finally I highlight some implications for nursing practice and give some recommendations for future research.

6.1 Discussion of the trustworthiness of the study

In this chapter I consider the methods I used in obtaining children’s views of their pain experiences. While seeking the truth in carrying out this research I have built on the following key principles of the qualitative research paradigm described by Woodgate (2001): 1. human beings are viewed as active agents constructing and making sense out of the realities they encounter, 2. multiple realities must be interpreted holistically and from various points of view and 3. a researcher and research participants share and mutually shape these realities. In all research, it is important to choose the methods that are appropriate for the people involved in the study, its social and cultural context and the posed research questions (Christensen 2004). For this reason, I consider if the practices I employed in this research process are in line with and reflective of children’s experiences (of pain), and their interests.

In the present study the informants were children who had experienced different kinds of pain during hospitalization. Using a range of flexible and age-appropriate techniques even four or five-year-olds are able to comment helpfully on their pain experiences. According to Polit & Beck (2004) the trustworthiness of a study increases by using several different databases. Similarly Greene & Hill (2005) have found that the combination of methods in data collection adds to the possibility of understanding children’s expressions. Triangulation of data collection: qualitative interviews, children’s thematic pain drawings and the children’s interpretations of these drawings helped to increase the trustworthiness of the findings. Moreover, according to Erzberger & Prein (1997) using a variety of methods reduces the possibility of bias due to a particular methodology or the omission of significant issues, and it also increases validity.
6.1.1 Trustworthiness of the interview data

Interviewing children is especially vulnerable due to various factors that affect the trustworthiness of the data (for review, see Paper I). As an interviewer, I adopted the role of a friend and a learner having a sympathetic interest in the children’s experiences in a hospital setting and willingness to understand it (Burgess 1984, Price 2002). It helped in building the rapport between me and the children and it also facilitated a more in-depth understanding of the children’s experiences.

An ideal unstructured interview is based on mutual interaction where the interviewer follows the interviewee’s story and generates questions spontaneously by reflecting on it. According to Briggs (2000) and McCann & Clark (2005) the format of the interview can be guided by an aid-memoire which is a broad guide to topic issues that should be covered in the interview. An aid-memoire does not restrict the order of the conversation but it permits revision based on the responses of interviewees. In my study the five research tasks constituted the interview aid-memoire. It assured consistency across the interview sessions and enabled balance between flexibility and consistency. The children in my study, including some of the youngest participants, proved skilled in one-to-one discussion with an adult researcher and the qualitative unstructured interview approach proved to be the most appropriate.

Gaining reliable data requires fusing together the different worlds and experiences of children and adults. O’Kane (2000) accentuated the importance of developing research practices in relation to children’s competencies which are different, but by no means subordinate to those of adults. I complied with Saywitz’s (1995: 113) comment which reflects the responsibility of the adult interviewer. According to Saywitz, interviewers must “capitalize on their (children’s) strengths, compensate for their weaknesses, and create an optimal environment for their remembering and communicating”. In this sense I offered the children an opportunity to draw as part of an interview strategy. Existing studies suggest that drawing helps to build a relationship between the researcher and the child (Bricher 1999). I found it to be an effective means for “breaking the ice” between the child and the interviewer. In my experience children remembered their pain experiences well. Among others, also Lev-Wiesel & Liraz (2007) found out, that when children were first asked to draw, their narratives were more detailed and more revealing of emotions compared to children who were asked only to verbally describe their lives.

As an interviewer I was an integral part of the research instrument. This required skills in questioning, probing and adjusting the conversation at an appro-
In order to fulfill my role I familiarized myself thoroughly with the methods of qualitative child interviewing (for review, see Paper I). When gathering the interview data I maximized the use of open-ended questions because children are less likely to make source errors when asked for open-ended, free call accounts than when asked specific questions (Dockrell et al. 2000, McCance et al. 2001, Roberts & Powell 2001) and identified the kind of open-ended questions that are more likely to produce stories. Moreover, I knowingly tried to avoid offering incentives for responding in a certain way, because children may respond inaccurately if they believe that the interviewer would prefer a particular response. If I noticed that a child did not understand my question I rephrased it in another way. Qualitative unstructured interviews enabled me to clarify the meaning of the responses I received. I made four preliminary interviews before the actual interviews and especially reflected on using appropriate types of questions based on the specific interview context. Because I succeeded in these as expected I included these interviews in the actual research data.

It is important to acknowledge that although this review has focused on the quality and trustworthiness of children’s reports, many of the factors discussed affect adults’ reports in similar ways.

6.1.2 Achieving trustworthiness in analysing the interview data

In order to assure the research findings to be as trustworthy as possible I evaluate my study in relation to the procedures I used to generate the findings and assess the trustworthiness of the study on the grounds of the general criteria of qualitative research (Lincoln & Guba 1985). A qualitative research process proceeds on the terms of the research data which is in the most salient position in the research process as a whole.

Lincoln and Guba (1985) suggest the application of truth-value, applicability (or transferability), consistency (or dependability) and neutrality to be used to describe the various aspects of trustworthiness in qualitative research. When considering the truth value, the equivalence of the research findings is considered between the interpretation of the research participants and the actual reality. Equivalence is always considered in the context where the study is conducted. The concept of credibility is also used interconnected with the truth value. (Lincoln & Guba 1985, Polit & Hungler 1999, Berg & Welander-Hansson 2000, Graneheim & Lundman 2004.)
Unstructured qualitative interviewing is particularly useful for exploring a topic broadly. However, there is a price for this lack of structure. Because each interview tends to be unique with no predetermined set of questions asked of all respondents, it is usually more difficult to analyze unstructured interview data, especially when synthesizing across respondents. (Kondracki et al. 2002.) I analysed the interview data using conventional content analysis in which the aim is to describe a phenomenon.

A critical issue for achieving credibility in content analysis is in selecting the most suitable unit of analysis (Graneheim & Lundman 2004). After reading through the transcribed interviews I re-read the data and identified the unit of analysis by examining the data line-by-line. According to research tasks I looked in each child’s descriptions for statements which were important for the contents of each research task and for the phenomenon I studied. The children’s original statements were a starting point for the analysis (Ryan & Bernard 2000). I defined a statement as a complete thought, which in its broadest sense was a whole grammatical sentence. It could also be shorter, even a single word, if a sentence consisted of several complete thoughts. The statements were part of one or several sayings of me or a child. I always defined each statement in the analysis on the grounds of its contents. (for review, see Papers II, III and V). Graneheim & Lundman (2004) warn about too broad units e.g. several paragraphs. They can prove difficult to manage because they may contain various meanings. This was not a threat to the credibility of the present study because the statements in my interview data were not as broad as described by the afore-mentioned authors. On the other hand, Graneheim & Lundman (2004) also state that too narrow units may result in fragmentation but they are not very categorical in this. An exception to this, according to them, is when one or several words represent a symbol or metaphor. The children in the present study answered sometimes very briefly e.g. giving only a single word. It was not a problem because it is natural to describe pain in a single word: an adjective, adverb or verb which all are easy to categorize. The children also used metaphors in describing their pain. In order to enable the reader to judge the credibility of my findings I have illustrated how I constructed the units of analysis, condensations and abstractions.

The credibility of research findings means also assessing how well the formulated categories cover the data so that no relevant data are excluded or included (Graneheim & Lundman 2004). Because different questions generate different responses, I categorized all the children’s statements and made a great deal of effort to analyze the data systematically to find themes and patterns and to create
categories. In doing this I carefully considered the similarities within the categories as well as the differences between the categories.

Wahlström (1992) states, that credibility is achieved if the researcher’s interpretation of descriptions of reality produced by the researched is thinkable. When reviewing my study in the light of the knowledge and experience I have of children and childhood in general, and of children’s pain experiences in particular and of researching them as well as children’s health and illness and child health care, I may interpret my report of children’s pain experiences as thinkable.

Assessing applicability (or transferability) means questioning to what extent the findings can be transferred to other situations or settings or other groups, or generalized (Lincoln & Guba 1985, Polit & Hungler 1999: 717). I attribute settings and circumstances as integral components of pain experience and as a result the findings of the present study cannot be transferred to other different settings or contexts. Consequently it is not reasonable to use applicability as a criterion of trustworthiness in this context (see Perttula 1995b). However, Graneheim & Lundman (2004) let the reader to decide whether or not the findings are transferable to other contexts. In order to facilitate applicability I have tried to present clearly and distinctly all the stages of the research process and report the research process explicitly.

Consistency (or dependability) means replicating the research findings with the same participants in the same context. Evaluation of the research context (Lincoln & Guba 1985) and reliability (Wahlström 1992) serve as criteria. These criteria are related to the way in which the method of analysis is suited for diverse cases. In this study it is not meaningful to use consistency as a criterion of trustworthiness because the basis of the researcher’s interpretation of reality is the experience of another human being. Since both I as a researcher and the children as partners in cooperation in my study developed and learnt from the experience we encountered in the research situation, we are no longer the same as human beings in relation to consistency. Consequently, the reliability of my interpretation as a researcher can be assured only by re-analysing again and again the experiences of new children (see Perttula 1995a).

Assessing neutrality means reviewing to what extent the findings are the product of the research participants and the research itself. It refers to the freedom of bias in the research procedure and findings. A major threat to the truth-value of a qualitative study lies in the closeness of the researcher-subject relationship. (Sandelowski 1986.) In other words, in what amount the research findings are particularly the product of the participants and of the research (Paper I). They should not
be biased by the researcher’s own motivations, interests and viewpoints (Lincoln & Guba 1985). Further, other contextual factors are likely to affect the trustworthiness of the study e.g. the setting for the interview. In adult-led settings, like hospitals, the child may feel pressured (Punch 2002a) because of the power imbalance between adult researcher and child. When collecting the data in this study I did not identify any pressure placed on the children. Instead, the children became interested in the topic easily and began to think about and relate vividly the examinations that they had experienced. This was shown, for example, by their tendency sometimes to whisper or shout and to act always in accordance with the intensity and atmosphere of the reported situation. The children seemed to be extremely grateful when they realised that an adult took them seriously and let them follow their own line of thinking. According to Dockrell et al. (2000) children’s cognitive capabilities interact with their memory and emotions, that is why in one situation a child may underestimate her/his views and in another she/he may exaggerate them. This is difficult to anticipate and recognize in an interview situation.

The criterion of neutrality is consistency, which means the possibility of coming into similar findings, analysis after analysis. Consistency represents how the methods of analysis distort perception of the phenomenon under study. (Perttula 1995a.) Roberts (1999) states that content analysis is a particularly reliable means of analysing qualitative data, because it is possible to confirm the coding by revisiting the data to check the stability over time. To increase the study’s consistency, I categorized the entire interview data and after three months I checked the categorization. To make the research process visible, I cited quotations from the children in the original articles. The time between the analyses was so long that memory had no significance in the analysis on the data. I counted the percentage of agreement in compliance with each research task according to the formula presented by Polit & Hungler (1999). The percentages varied between 87 and 93%. However, in Perttula’s (1995a) opinion, consistency can never be absolute because a mental chain of thoughts from the experience of the researched and from the expression of this experience to the experience of the researcher and to the expression of this experience does not progress unchanged, as I earlier stated, because of new experiences and learning.

6.1.3 Validity of drawings as projective method

Children like to draw human figures and drawing people remains popular throughout childhood. Researchers disagree, however, about the validity and robustness of
using children’s drawing as an indicator of cognitive and emotional status. Some argue that drawings lack validity, reliability and theoretical ground as an indication of children’s emotional and mental health status (Sattler 1988, Kamphaus & Pleiss 1991, Motta et al. 1993). On the contrary, others consider drawings as children’s natural expression involving multiple meanings, which well illustrate their developmental capacities, mental health and relevant experiences (Koppitz 1968). Some empirical evidence is available about the effectiveness of drawing as a projective method in assessing children’s internal feelings and thoughts about painful issues and that they can give an illustrative picture of the child’s psychological state during hospitalization and pain (Carrol & Ryan–Wenger 1999, Veltman & Browne 2003).

The projective value of children’s drawings for assessing intelligence and psychological or emotional disturbances has simultaneously been supported and challenged over the years (Gross & Hayne 1998, 1999). During the last decade children’s drawings are being revisited as a potential facilitative method for communication with children and numerous studies demonstrate that drawing facilitates children’s abilities to communicate and talk particularly about those events or concepts they might otherwise find difficult to describe (Butler et al. 1995, Gross & Hayne 1999, Wesson & Salmon 2001, Pipe et al. 2002, Stafstrom et al. 2002, Veltman & Browne 2003, Driessnack 2005).

Interpreting the symbolic significance of young children’s drawing is a matter of substantial concern and controversy. As Thomas & Jolley (1998), Lilienfeld et al. (2000) and others have emphasized, the often ambiguous nature of drawings must be acknowledged and information of drawings should not be used in isolation. A content analysis of children’s thematic drawings can be obtained in a variety of ways. When using an interactive way, as I did, children are asked for their own interpretation of their drawing. Also Driessnack (2005) encourages shifting the focus from what the children draw to what the children say about what they draw. For this reason I asked the children to talk about what they had depicted.

In spite of the fact, that the projective value of children’s artwork has been challenged over the years (Bardos 1993, Kamphaus & Pleiss 1993, Motta et al. 1993, Naglieri 1993, Abell et al. 1996), drawing may still play a valuable role in clinical settings with children (Gross & Hayne 1998). According to Stefanatou & Bowler (1997) using a projective technique such as drawings gives some advantages in order for children to express their pain experience. Drawings are not dependent on language abilities and their administration usually does not cause distress to them. Veltman & Browne (2003) state that, in general, projective draw-
ing techniques are less susceptible to faking than self-reporting. According to Docherty & Sandelowski (1999) the call to hear the voices of children requires shifting from seeking information about children to seeking information from them. Whether or not children would draw what they find easy to depict, whether experience would affect what was depicted, whether the content of the drawings was affected by environmental factors, my experience is that children’s drawings are a valuable source of information both for research and clinical practice.

I found drawings to be a priceless catalyst for meaningful conversation as well as an excellent strategy to increase my ability to hear children’s stories about their pain experiences – in their own voices. I regard children’s drawings as uniquely personal statements. The response of health care professionals gives value to children’s drawings and also gives a framework for respecting the children who shared them. When sharing their drawings children present us as health care professionals or researchers with a great responsibility. There is a story in children’s drawings and that story needs to be explored. In order to do that further investigation is needed and drawings should be accompanied by children’s personal stories so that the drawings can be placed in the context of children’s lived experiences.

It is said that a picture is worth a thousand words. Drawing may facilitate memory performance also in young children (Butler et al. 1995, Gross & Hayne 1998). It is possible that drawing inadvertently provides children a focus other than the interviewer. According to Gross & Hayne (1998) this shift of focus decreases both the adult bias and the social demands for the children, resulting in a more child-driven report rather than an adult-driven one.

6.1.4 Methodological consideration: Thematic drawing and Draw-a-Person-procedure

Thematic drawing. I analysed the contents of the drawings using two methods. The first focused on the expression of pain and I applied a modification of the classification method of the children’s pain drawings by Unruh et al. (1983) and by Jerrett (1985). I used the children’s descriptions about their drawings as information for categorizing and based the categorization solely on the content commonalities in the children’s pain drawings, without any attempt to interpret the state of mind of the drawer. My study clearly demonstrated that children’s pain drawings can be reliably categorized by content. The validity of this procedure is enhanced by the fact that most drawings could be categorized and therefore only 16.2% of the hospitalized children’s drawings and none of the healthy children’s drawings had to be
assigned to the non-specific category. As an indicator of reliability, I analysed the contents of all the children’s pain drawings twice at a three month interval. Agreement on the ratings was 83 percent.

Secondly, we (R-LK and R-LP) classified the children’s drawings on the basis of more general themes that did not focus only on pain expression. The analysis was based solely on the children’s drawings (and not on their descriptions), involving an interpretation of the atmosphere in the scene, and emotions and relational quality of the drawing characteristics. For the reliability test, all the contents of the drawings were re-analysed by a student specializing in children’s drawings. The Kappa value of .71 was satisfactory.

Children like to draw about their own pain or pain in general. In the hospitalized group, older children refused more often than younger children. This corroborates the study of Ryan–Wenger (2001) who reported that it is difficult to encourage teenagers and adults to draw for research or clinical purposes.

**Draw a Person.** Children’s drawings are frequently used in educational settings for evaluation and in clinical settings for diagnosing the quality of family relations, emotional disturbance and subconscious processes (Koppitz 1968, Mortensen 1991, Ryan-Wenger 2001, Wesson & Salmon 2001). The validity and theoretical bases of projective methods, such as drawing, is a constant source of controversy. Considerable criticism has been expressed whether children’s drawing can indicate their cognitive capacity, emotional status or experience of stress and trauma (Sattler 1988, Kamphaus & Pleiss 1991, Motta et al. 1993). However, there is also increasing evidence about the validity and reliability of Draw-a-Person procedure. Its emotional dimensions correlate with emotional distress and behavioural problems (Matto et al. 2005), and cognitive dimensions with standard methods of IQ (Intelligence Quotient) and other cognitive capacity (Lassiter & Bardos 1995, Punamäki et al. forthcoming). Also because drawing is one of the most natural ways of expression among children, it can provide information about the drawer himself (Mortensen 1991). This study with a small sample size and specific illness-related focus can support the usage of quantitative scoring of children’s drawings, as the results show meaningful differences between hospitalized and healthy children. The finding of lower cognitive performance among hospitalized children corroborates with earlier research by Berger & Thomson (1998) who used standard cognitive tests. The results are based on the scores on standardized, theoretically-founded and detailed dimensions of drawings indicating the cognitive-emotional functioning of children. Dunn et al. (2002) have recommended detailed and well-defined criteria for developmental aspects when making conclu-
sions about children’s drawings. Earlier analyses of the drawings of ill children have predominantly focused on the contents, thus ignoring the cognitive and developmental aspects.

The interrater reliability of the DAP: QSS based on a random selection of 30 drawings, was scored. The Kappa coefficients were satisfactory, ranging between .66 and .72. Naglieri’s (1988) DAP: QSS dimensions have been found to be a valid and reliable indicator of cognitive abilities in a sample of 758 Finnish children (Punamäki et al. forthcoming), which corroborates with earlier evidence of the DAP: QSS correlating standard measurements of cognitive capacity (Lassiter & Bardos 1995).

The reliability indicating internal consistency between all dimensions of the DAP: SPED was .87, and the interrater reliability indicated by Kappa and based on 30 drawings was satisfactory, ranging between .65 and .75.

The size of the sample was sufficient to answer the questions, yet some concerns exist about the generalisation of the results and other methodological issues. The criterion for the control group participation was that children were healthy and did not have a current illness needing hospitalization. The criterion was fulfilled by the fact that they were able to participate in day care and school. However, it may not be possible to control all possible biases. Both groups might have included children having a family member who was ill or hospitalized. Further, whilst undertaking the drawing task the children were in different environments. For example, the control group drew in the day-care centre or at school among peers and familiar adults. Although a majority of the hospitalized children had a family member with them, they drew their pictures in a strange hospital setting. Twelve children did the task alone with the interviewer. It is not possible to control all such external influences.

6.1.5 Limitations

There are limitations in this study. The nature of pain itself limits the generalization of the study. Due to the small sample size, the findings should be taken with caution. There were two children who refused to participate in the interview study for various reasons and six children who did not want to carry out the drawing task. This can be seen as a dilemma in conducting research with ill children in that, due to the nature of the child’s illness, the child does not want to be bothered and ethically she/he should be approached (Board & Ryan-Wenger 2002). However, these children might be the most vulnerable and in need of study because of the
risk of psychological and behavioural problems (Jones et al. 1992). An implication of the observed difference in the mental ability of the pain and non-pain drawing is the need to acquire multiple drawings if one wants to measure the true cognitive ability of the ill child.

6.2 Discussion of the findings

In this section I discuss the findings of my study. I divide this discussion into five sections. In section one I focus on challenges to seeking young children’s views by conducting a qualitative unstructured child interview (Paper I). In section two I consider the sources and causes of hospitalized children’s pain experiences (Paper II). In section three I build on these by examining children’s descriptions and perceptions of pain as well as their views of the purpose of pain (Paper III). In section four my discussion is on the contents as well as cognitive and emotional characteristics of children’s thematic pain drawings (Paper IV). In section five I reflect on the children’s opinions about pain management (Paper V).

6.2.1 Qualitative child interview

Conducting qualitative research with children involves different challenges and research techniques to research with adults. The researcher needs to examine beliefs regarding children’s competence, address the inequality of power in the adult-child relationship, and bridge different communication styles. The researcher can employ a variety of techniques and adaptations to help children express themselves.

There are many challenges associated with eliciting the views and opinions of children by qualitative child interviews. These are dependent, in part, on the phenomenon under study and on the research tasks addressed and, in part, on the developmental age and abilities as well as the situation of those whose views are sought. A small part of the literature offers some solutions to these challenges (e.g. Bricher 1999, Dixon-Wood et al. 1999, Ensign 2003, Kortesluoma et al. 2003). In spite of these, there is still little concrete guidance available for interviewing children.

On the basis of my experiences, it seems fair to state that good preparation is vital (for review, see Paper I). The interviewer may have a positive or negative effect on the interview (Krähenbühl & Blades 2006). The researchers should always plan their method of research in detail. The feasibility of qualitative child
interviewing as a method of data collection depends especially on the interviewer’s ability to gain children’s confidence and to become involved in the interaction between themselves and the children. Punch (2002) says that it is misleading to assume that all adults are able to build rapport with children. Several authors (e.g. Coyne 1998, Morrow 1999, Morgan et al. 2002) have noticed the problem and share advice in establishing rapport prior to the interview. Interviewing children requires adopting the child’s language and formulating concise and clear questions (Mahon et al. 1996). Skill and experience are required to elicit the appropriate answers that actually represent children’s points of view. In the end, children certainly know more about what they know than interviewers do. The purpose is to get children to talk about what they know.

6.2.2 The sources and causes of hospitalized children’s pain experiences

Despite an upsurge of research during the last decades, most studies on child pain have focused on one type of pain problem, rather than on whether children had any pain problem. In hospital settings, it is often necessary to obtain young children’s accounts of pain by probing emotionally laden events that they have experienced. Knowing the source of the pain helps determine the best way to treat it. To maximize the effects of pain management, healthcare professionals need to know which of the children suffer pain, the circumstances in which pain occurs and how it is experienced.

The children in my study remembered their pain well. Also other researchers have found that children’s memories of medical care are vivid and accurate (Docherty & Sandelowski 1999, Gobbo et al. 2002, Baeyer et al. 2004). Both adults’ and children’s pain experiences are an unpleasant mixture of sensations and emotions. Memories of previous pain experiences cause anxiety and prejudice about the upcoming pain experience. They can also affect children’s acceptance of later health care interventions and have a significant impact on future coping with pain (Salmon et al. 2002).

All the children in my study had experienced pain in different situations while being hospitalized (For review, see, Paper II). These pain experiences arose from the children’s basic illnesses, injuries caused by accidents or surgical procedures to cure them. Painful situations included repeated diagnostic procedures, medication, treatments and therapeutic interventions. The children also named specific pains,
such as headaches or stomach-aches, which many of them had suffered. It is significant that the children found even an assault on their psyche as painful.

In addition to pain caused by illness and surgical operations, the main problem seems to be pain caused by diagnostic procedures. The findings of my study are in line with the findings of earlier researchers (e.g. Eland & Anderson 1977, Savedra et al. 1982, Wong & Baker 1988, Cummings et al. 1996, Hägglöf 1999, Pölkki et al. 1999, McGrath et al. 2000, Coyne 2006a) who define invasive procedures as extremely pain provoking procedures during children’s hospitalization. There is no arguing with the fact that an injection hurts. A needle arouses a variety of negative responses from most children. All the children participating in my study were familiar with these situations, and they mentioned them as being among their most painful experiences.

It seems that, children do not become accustomed to pain. A child may interpret a painless procedure to be extremely painful or unpleasant due to its psychosocial context. In a new situation, children feel unsure about what is going to happen and how they should behave. The amount of pain does not necessarily decrease when the painful procedure is repeated, but the fear that the child feels for a situation may reduce and thus help her/him to cope with the situation. The relationship between pain and fear is complex, as fear increases pain. If the patient is very fearful, even minor pain may become intolerable. The physical dimension of pain can be greatly modified by the unique emotional context of each child.

The findings indicate that children in a hospital setting may be experiencing severe pain, even though they do not belong to groups known to have pain, such as surgical or cancer patients. For example, Taylor et al. (2008) concluded in their study of pain in hospitalized children that their pain was under-recognized and under-treated, even though it occurred commonly across all age groups of children and was moderate or severe by intensity. Thus, it is highly probable that any child in the hospital may be experiencing pain regardless of diagnosis, as attested by several authors (see e.g. Cummings et al. 1996, Perquin et al. 2000, Breau et al. 2003).

In summary the findings suggest that hospitalized children continue to suffer pain. If healthcare professionals take the claim seriously that “pain is whatever the experiencing person says it is, existing whenever she or he says it does”, the question arises, what does the medical diagnosis, which is built around physiological and biomechanical conceptualizations of the body, convey to the suffering child? In essence, there is a person (child) who has pain and disrupted life. Therefore, attention should be paid to every single child in the hospital. Children are able to
report and describe their pain and they should be regarded as experts on their pain in order to maximise the options for pain management.

6.2.3 Hospitalized children’s descriptions and views of the purpose of pain

Pain assessment is an intrinsic component of pain management. Health care professionals call for objective measures of pain intensity and an understanding of the factors causing pain for an individual child (McGrath 2005). There are more than 60 pain measures available to be used with children and adolescents (see McGrath 1998, McGrath & Gillespie 2001, Stevens & Frank 2001). However, these provide only a one-sided viewpoint and an indirect estimation of pain attempting to objectify the subjective phenomenon. The child’s self-report is still the single most reliable method for assessing pain (Pasero & McCaffery 2005, Goldman 2007). In order to capture the subjective experience of each individual child, projective techniques such as qualitative child interviewing are needed. Language is an essential human tool and the way people (children) describe their pain is worth of study.

In describing their pain the children used a number of self-reported pain words (For review, see Paper III), describing physical pain and mental pain as well as evaluative aspects of pain. Also several previous studies (Kloos 1999, Cheng et al. 2003, Alwugyan et al. 2007) demonstrated that children in their studies were able to describe their current pain in their own words. The amount of information and the complexity of descriptions hospitalized children generated in this study (for review, see Paper III) corroborates the work of earlier researchers (Natapoff 1982, Boruchovitch & Mednick 1997, Stanford et al. 2005a), who suggest that growing children experience important increases in their abilities to discuss more abstract concepts and view phenomena from multiple perspectives that, specifically in the case of health, incorporate physical as well as mental dimensions. Certainly, language serves as an important and meaningful way of pain expression, as noted also by Stanford et al. (2005b).

Child characteristics, such as cognitive level, previous pain experience and cultural background generally shape children’s interpretation of pain (Chen et al. 2000, Chambers et al. 2002, Alwugyan et al. 2007). Historically health care professionals have been reluctant to recognize children’s potential to understand their illness experience. Researchers and health care professionals should not stare at the supposed abilities of children and should not underestimate the awareness and maturity that some children possess when addressing issues of concern to them.
selves. Children’s stories in my study reflect the fact that their pain is multidimensional, composed of knowledge elements gained by multiple experiences. The findings challenge the focus of children’s cognitive limitations.

Children routinely find themselves having to manage the contingencies in adult-led institutions, such as medical settings, school classrooms, and within the family of course. Thus, it is interesting to speculate on the meaning of the social context in which I conducted the interviews and the children reported their pain (Weisse 2004). Did my gender and professional status or my other characteristics influence to children’s pain reporting, as suggested by Kállai et al. (2004)? How did they influence a wealth of information of aspects about the children’s pain descriptions?

Jongudorngart et al. (2006) argue that individual experiences of pain are social because they occur in a specific socio-cultural context. My study generated a qualitative exploration of the specific purposes attributed to pain by children living with pain. It seems from the data that hospitalized children assign a wider variation of purposes to their pain than I expected. Difficulties in identifying the purpose of pain, are worth emphasising, because expressing pain and coping with pain may be influenced by the meaning given to pain. This understanding should enable further development of knowledge related to nursing and caring for children living with pain, particularly those raised in Northern Finland. The finding strengthens the belief in children’s potential to understand far more about their experiences of pain and hospitalization than previously recognized.

Children’s accounts of pain provoking and emotionally laden events offer a unique window into their internal world and at the same time provide privileged information that cannot necessarily be obtained from significant others in their lives. The stories of even young children are likely to convey more information of their pain experiences than other self report measures, like a variety of scales, such as numerical and visual analogue and face scales or colour and poker hip tools or pain ladders, because these tools fail to anticipate the complexity of the wording which the children in my study used.

Humane care of children includes adequate pain assessment and management. Descriptions of hospitalized children’s experiences with pain are crucial to advancing the knowledge and management of childhood pain in a hospital setting. Children’s reports of pain provoking and emotionally laden events inform health care professionals about the nature of the child’s experience and may also provide valuable information about how the child has interpreted his/her experience, providing a basis for intervention. Improved clinical practice in the management of
children’s pain is contingent upon an improved understanding of hospitalized children’s interpretation of their pain experiences.

### 6.2.4 Hospitalized children drawing their pain

Drawing is a universal language of children and the use of drawing has been widely recommended as a means of assessment and communication with children (Malchiodi 2001, Ryan-Wenger 2001, Monsen 2003, Driessnack 2005). Experiences of illness, pain and hospitalization are highly stressful (Wright 1995, Shields 2001, Kennedy et al. 2004) and children at any age face difficulties in expressing their meaning and significance. The results of my study show that children’s drawings can elicit salient information about their views and experiences, as suggested by others (O’Malley & McNamara 1993, Ryan-Wenger 1998, Wesson & Salmon 2001, Veltman & Browne 2003, Matsumori 2005). They show meaningful differences between ill and hospitalized and healthy children in the cognitive and contextual dimensions of their pain experiences. However, the results concerning the emotional experiences of hospitalized children were counter intuitive, showing more emotional disturbances among the control group children (For review, see Paper IV).

The differences in thematic content indicate higher demands, distress and strain among hospitalized children, thus concurring with earlier research (Unruh et al. 1983). Furthermore, the findings of the present study show that the hospitalized children more often experienced themselves as targets of medical procedures. Only 8% of them drew their own actions aiming at managing the pain, which contradicts the results by Unruh et al. (1983) showing that sick children most often drew themselves doing something to cope with pain. In my study, the drawing contents of hospitalized children expressed technical, non-human, and operational aspects of pain, indicating control and non-emotionality. This was in great contrast to the healthy children’s ideas of pain, which involved the family coming together, seeking and receiving consolation and a deeper expression of emotions. There were also similarities between the groups, both hospitalized and healthy children preferred to draw themselves in pain or a part of a person in pain or placed their pain in a certain part the body. This is in line with Stefanou & Bowler’s results (1997).

The results reveal that hospitalized children showed a lower cognitive performance than their healthy controls when expressing pain. This finding supports Perrin & Gerrity’s (1981) research which suggests that especially older children who
are frightened of pain may have a tendency to regress to a more primitive level of reasoning. The finding is also in line with the findings of Stefanatou & Bowler (1997) who examined self-drawings of children with sickle cell disease and concluded that pain crises affects children’s cognitive functioning, and Wickström (2005) who noted that some children may show regression during hospitalization because of stress. Moreover, Peterson et al. (1995) stated that children regress in stressful situations and medical conditions may limit their ability to draw. The reason for the low cognitive performance level may lie in the fact that illness and frequent hospitalizations interrupt children’s school participation and thus training of cognitive skills (Stefanatou & Bowler 1997). Another explanation may relate to the children’s motivation and concern about their illness. The poorer cognitive quality, lack of human details and decorations in the drawings may reflect a lack of concentration and energy, which is sapped by illness and fronted by ‘being brave and enduring’. The adult-like control and formality depicted in the drawings of the hospitalized children supports a multiple interpretation of cognitive aspects in child development.

Contrary to the expectation, the control group children expressed more emotional disturbance than the hospitalized children, indicated by strongly shaded and disintegrated drawings. No group differences were found in the total emotional status scores. Two alternative explanations may be provided. Parents, siblings and friends care for ill and hospitalized children, which emotionally compensates for their suffering. Hospitalized children receive attention and love, which reflects their harmonious emotional development. On the other hand, the control group may include children with acute family problems and conflicts in their lives, which explains their greater emotional disturbance.

Children use drawings and pictorial representations as a way of expressing their feelings about themselves and their world. My study demonstrates that children's pain stories can be read from their pain drawings. Thematic drawing served as a pictorial narrative of pain experiences in which the children took part in the hospital setting. Malchiodi (1998) highlights the dual role of children’s drawing as a narrative form. Drawing enables children to express their individual stories through a developmentally appropriate form of communication and it provides a focus for talking about their drawings. However, according to Clements et al. (2001), too often clinicians and researchers disregard children’s explanations of their drawings and instead substitute their own explanations. Children’s drawings and their accompanying explanations or stories are self-controlled. Children deter-
mine what experiences, emotions, or memories they share. As health care professionals we should hear their interpretation.

The evaluation of children’s thematic drawings seems to be a relatively simple and useful aid in clinical practice to determine children’s pain-related emotions. Naglieri’s DAP: QSS (1988) and DAP: SPED (1991) procedures for analyzing drawings are excellent ways for a child health professional to assess and monitor a child’s emotional and developmental progress during a physical illness or hospitalization. Additionally, drawings may provide guidance for intervention aiming at pain alleviation and at reducing distress and anxiety. The findings strengthen my faith in using children’s drawings in clinical practice.

6.2.5 Pain alleviation methods used by children and their expectations of other people’s help

Children have their own perspective on their experience of pain and of hospitalization. The children reported high levels of knowledge and understanding gained from their experience of pain. The interviews showed that even at a young age, children’s experiences of pain enabled them to make decisions about their pain alleviation methods that were in their own best interests (For review, see Paper V).

The variety and complexity of children’s responses to their pain management suggest that children try and can alleviate their pain (For review, see paper V). The children in this study demonstrated a variety of self-management skills in relieving their pain and in attempting to gain control over the pain situation. They used, among others, distraction, imagery, relaxation and behavioural management as self initiated pain alleviating methods. These are generally safe and give children a sense of control over the pain sensation. It may be supposed that children are more adept than adults in using psychologically based therapies, presumably because they generally do not have a preconceived assumption about their potential efficacy as adults may have. Apparently ill children who are hospitalized and repeatedly involved in medical and diagnostic procedures become adept at identifying and implementing a repertoire of pain alleviating methods.

The children also reported expectations concerning professional help. They expected professional competence which manifests itself in technical expertise. They called for empathy. Their coping could be enhanced by knowledgeable, gentle and supportive staff behaviour. Schmidt et al. (2007) emphasize children’s continued need for comfort and conversation. The findings of my study demonstrated that children want to know and tell about their pain. Similar findings have emerged
in other studies. The children in Carter et al.'s (2002) study sought to be involved in discussions about their pain. In Horstman & Bradding’s (2002) study as well as in Smith & Callery’s study (2005), children expressed a desire to get clear and honest information about their condition and treatment. Mårtenson & Fagerskiöld (2007) concluded in their observational study that children tried to enhance their situation as much as possible by finding out as much as they could and by sharing their own knowledge with the health care professionals. However, e.g. Twycross (2007) states that surprisingly few nurses in her study spoke with children about their pain. Moreover, Richards & Hubbert (2007) reported that expert nurses had difficulties in accepting the adult patient’s description about his/her pain. It seems as if there is a conflict between the needs of children and the knowledge and attitudes of health care professionals. It is a challenge to meet the personal needs of children in paediatric pain care without having information about how they experience the situation.

Moreover, as found in previous studies (Carter et al. 2002, Runeson et al. 2002) the children in my study valued the care and attention provided by significant others, especially by parents. Children’s anxiety can be high when they are in painful situations. Parents have an important role in providing emotional support. They know their child best of all and may sometimes be the most appropriate people to give explanations and comfort their child. A trusting relationship between people is the basis for comforting (Ångström-Brännström et al. 2008). In order to attain comfort the child needs to trust the nurse (Morse 2000). Maybe establishing trust between the child and the nurse was incomplete, because some children in my study regarded professional support with suspicion and called for empathy and care by “being there for the child”.

Listening to children’s stories and feelings optimizes care by allowing shared communication, as confirmed by Alderson et al. (2006). It increases children’s control in a confined and often new environment. Children’s conceptualizations of their pain management can guide development of child-centred services and practice. Children’s descriptions of their self-initiated strategies that they used to relieve their pain and their thoughts of pain management and help from others as identified in this study provide interesting insights and challenge traditional assumptions.

Situation specific factors on the specific circumstances in which a child experiences pain vary dramatically. These can include the children’s level of understanding, their activities, and their feelings in the situation. Some of these can intensify pain and distress. (McGrath 2005.) Working together with children, par-
ents and health care professionals can dramatically improve children’s pain experience and their perceived pain relief. Further, children’s competence supports approaches based on children’s rights and their responsibility for their own care in partnership with health care professionals and significant others.

Helping pain is often simple (For review, see Paper V). Ill children who are hospitalized repeatedly or for long periods or experience numerous investigative procedures are adept at identifying and implementing a repertoire of pain alleviating strategies and developing patterns of methods with significant others. Children are not demanding in terms of the complexity of methods, instead these methods are accessible to everyone who is truly interested in relieving pain in children. Children’s coping can be enhanced by familiarity and knowledge and by the respect and patience of gentle, supportive, and competent health care professionals. Caring is a fundamental concept in nursing, and using a multidimensional approach focusing on the whole patient, is an effective way to treat paediatric pain and incorporate caring into practice.

6.3 Implications for nursing practice

The purpose of my study was twofold – to present an overview of hospitalized children’s pain from their perspective and factors for its effective management verbalized by the children themselves; and to present a mandate for change. The research raises a number of issues for involving children in the development of pain assessment and management within health care services. The results of the study show that pain is an important factor in children’s interpretations of their illnesses and the treatments that they receive. To maximize the effects of pain management, those nursing children need to know which children suffer pain, the circumstances in which pain occurs and how it is experienced.

The results of the study into painful situations cited by children show that there is a need for some recommendations to be made to health care staff. First, the sensation of pain, i.e. the pain experience, is a very personal matter. The outcome of the study disproves claims that it is supportive to tell simply the child about the painfulness of a procedure that they are about to experience, as each child perceives sensations differently (For review, see Paper II). The healthcare professionals should always listen to the voices of children and assume that the child’s report of pain is valid.

Clinicians and nurses in practice need to become more aware of the value of children’s self-report of pain, and the limitations of relying on children's behav-
journal manifestations to judge pain intensity. Drawing accomplishes identification and a better understanding of children’s emotional status. Thus, health care professionals should incorporate HFDs as a part of every child’s examination, because children may not be able to discuss or may be unwilling to discuss their emotional status. Since no similar use of the interview and drawing technique has been reported in previous research in nursing in Finland, this study may act as an indication of the possible benefit of its use in clinical settings.

Children's unique perspectives should be sought regularly and their data included in ongoing programs of quality assessment. When only parents are queried, important and insightful perspectives from children are missed and these could improve care quality. Health care professionals need to acknowledge the need to listen to children and the importance of finding out what matters to children as health care users in their own right.

The involvement of children in improving care quality is a new idea, although this is now embedded in practice the United Kingdom (e.g. Gibson et al. 2005, Tisdall et al. 2008) and to some extend in Finland too (e.g. Sorsa et al. 2006). The evidence of my study suggests the development of a listening and communicating culture in a hospital setting as urged by the young participants of my study. The use of child-friendly approaches, and hearing children’s voices in matters dealing with their pain management, gives children control of their pain and may thus result in positive outcomes for the personal development of child patients and professional development of health care providers.

6.4 Recommendations for future research

The findings of the current study strengthen my faith in using children as research participants and informants, as well as their thematic drawings in clinical practice and encourage further research in this important area. The moral obligation of nursing is to shed light on the experiences of those most vulnerable within health care. Qualitative research designs have the advantage of shedding more light on new phenomena under study and in generating research hypotheses which can later be tested experimentally. Although the increasing call for evidence based health promotion has impacted upon many areas of practice, in these debates research with children has rarely been considered, except as potentially problematic (Alderson et al. 2006). The development and strengthening of research with children requires enlisting the active collaboration of children themselves. Research with children can achieve its aims only by partnership with the indivi-
als whom we wish to benefit from this process. To that effect I made a number of recommendations where further research is still needed:

– Due to inconsistencies reported in the literature regarding hearing of children’s voices in the development of health promotion strategies, health education and research, I recommend further research addressing children as research participants.

– Since very few studies address evidence based pain management in children, I recommend that this area of research receives more attention in future. More research with children rather than on children is required in order to expand the discoveries of my study.

– In order to enhance clinical pain assessment and management it is important for further research to examine the utility of pain language among children.

– Drawing pain warrants more attention. It is possible that drawings are among the best sources of information for assessing children’s pain experiences as well as related emotions and feelings. This hypothesis deserves further testing.

– In order to delineate the nature of information elicited using children’s drawings when compared with the nature of information elicited using more traditional self-report methods further research using mixed methods is needed.

– Very little is known about how different research contexts with a range of different facilitators and a variety of stimulus statements might affect what children produce as data. I claim further research here too.

– Children deserve the benefit of systematic research. Children’s preferences, beliefs and understanding of pain interventions need to be examined in future studies. These will generate empirical data on which to base health care professionals’ pain management education and clinical practice.

– Scientific developments in the field of pain in children are contributing to a rapid upsurge in interest. It is assumed that the implementation of knowledge gained through research will lead to effective assessment and management of pain in children. This assumption deserves nevertheless to be investigated.
6.5 Concluding ethical considerations

The participation of children in research is complex. Despite the changing view of children, health care professionals continue to see children as vulnerable, incompetent and in need of protection because of their compromised health status (Christensen 1998, Neill 2005). This might mean protecting children from involvement in research. Consequently, it may result in a different kind of knowledge and even less knowledge about children and their affairs for the development of care and interventions for children. I agree with Neill (2005) who states that it is unethical not to conduct research with children in the name of protection. I found that the children involved in my study were capable of deciding whether or not they wanted to be interviewed. Coyne (2006b) found out that both parents and children (9–11 years-old) understood children as being capable of making decisions about their participation. Moreover, what a child eventually shared with me was decided by the child. They also decided the time of the interview (cf. Miller 2000a, Greene & Hill 2005) and had an opportunity to listen to the tape-recorded interview.

Taking part in a research study may have an impact on child participants. Mahon et al. (1996) and Neill (2005) emphasize researchers’ need to consider the impact of participating because the children involved may become distressed during data collection. Some researchers state that causing harm to children during pain research is unavoidable (Kankkunen et al. 2002) because they are required to recall a painful event. The duty of every qualitative researcher working with vulnerable populations, such as children, is to conduct research in the most ethical way possible (Ensign 2003). I checked the children’s feelings during and after each interview. Although the study was not directly therapeutic for the children, in my mind the opportunity to discuss their pain experience can be seen as potentially beneficial.

The duty to benefit another (beneficence) as well as the duty to do no harm (nonmaleficence) means that health care professionals are obliged to provide pain management to all patients, including also the most vulnerable ones (Herr et al. 2006). Every person with pain regardless of being or not able to self-report pain deserves accurate recognition, assessment and treatment. Since, health care professionals should search for the most appropriate methods for assessing and managing pain in children. Too often, clinical decisions about the care of children have been based on the assessment of proxies and children’s thoughts about the methods of pain management have not been sought. However, children should have a say in what happens to them. Encouraging their involvement in pain assessment and management should be done out of respect for their rights as individuals and the desire to give them a sense of ownership in what happens during hospitalization.
7 Summary and conclusions

In my doctoral study I attempted to fill some of the gaps in previous research on children’s pain assessment and management and sought to explore children’s experiences of pain in hospital setting as described by the children themselves. The findings showed that research and data collection with children is effective and has given them a voice. I reflected on the importance of giving children a voice in the research data. The data have shown that children experience pain, are able to assess and describe their pain, and they react to and cope in different ways with pain. Moreover, my findings challenge the tendency for unfounded assumptions about children and childhood. Shaw (1996) highlights one of these, namely the question of childhood as somehow a homogenous entity. Instead, my findings reiterate Eiser’s (1990) statement that hospitalized children cannot be treated as a homogenous group. The application of qualitative research to the experience of childhood pain is essential if we want to understand both the commonalities and diversities of childhood as one phenomenon and pain experience as another and how they both interact in the child.

In conclusion, the combination of qualitative child interviews and drawing techniques constituted a major step forward in my attempts to access children’s conceptualizations of children’s pain related issues using child-appropriate methods. Most importantly, I suggest that health related research with children must be premised on an appreciation of the social context and the world of children. Moreover, researchers need to create the potential for children to have their own ideas and explanations heard and understood.

Children in pain who have contact with health care services must be heard and the rights of children to obtaining and giving information must be recognized. Health service providers working in the field of child health who claim to be responsive to the needs of its users are not able to effectively plan their services for children without eliciting children’s views. This means that it is essential for them to be well informed about contemporary issues pertaining to child development, communicating with children and being familiar with the ways in which children conceptualise the world. Even more importantly, service providers need to apply these principles into practice. This ensures that children are given a voice which is listened to and taken into account. By continually revisiting the ways in which hospitalized children are currently thinking about, conceptualising and understanding the aspects of their pain, it is possible to push forward the boundaries of pain alleviation practices in ways that secure children’s best interests. The findings of
my study convey that children can communicate completely their experiences of pain and health care. The use of appropriate, creative data collection techniques can enable children to express their views and be supported to take an active role in their health care and in research. It is also possible to adopt the methods of data collection and analysis of this study into other vulnerable populations of health service users.
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Appendix 1. An example of children's pain descriptions in the context in which the experience had emerged
Appendix 2. An example of an interview intuitively transcribed by content areas according to meaningful statements

Number of interview, date and ward

A ten year old girl with burns. Scalded herself with hot water from a thermos, which caused burns on her legs down to her feet and her lower belly. Interview conducted in the patient’s room, with the father present for part of the time. A bright, active child, she asks if there are no germs on the pens I give her. When asked to draw a picture of her pain, she does so readily and without difficulties. She describes her drawing as “a terrible mess” but so, she says, is her pain too. There are many interruptions in the course of the interview: a visit of her doctor, her wounds are sprayed, there is an alarm from her drip, and the drip bottle is changed. In the space of the 70 min interview, there’s about 20 min of actual interview time.

R-L: First, I’d like to ask you what sorts of things have caused you pain? CHILD: Huh, you mean, when I’ve felt pain? R-L: Yes, like, think about what has been the worst pain you have ever felt. CHILD: That’s when, that’s when they take the bandages off. That really hurts, that’s really difficult, ‘cause I don’t see my legs and feet. Yeah, that pain, it doesn’t really help a lot, maybe a little. Not a lot, though.

R-L: You said that changing the bandages really hurts. How does it feel? Can you describe how that feels? CHILD: It’s as if they tore off my skin. That’s so horrible, as if something awful was pulled off my skin, something that’s sticking to it really hard. And then I have to, like, when the dead skin was pulled off, when they washed it. That’s real horrible, as if something horrible was ripped off my skin. I hate that.

R-L: Well, and what’s the next worst thing? CHILD: (thinks for a while) I guess it’s that my legs will remain all wrinkly. ‘Cause I don’t want that they do, that there are such clear marks on them. And I don’t want them to be so ugly wrinkly. R-L: Well, I suppose they know how to treat them quite well... CHILD: Hmmm. R-L: You’re worried that they stay wrinkled? CHILD: Yeah.

R-L: Listen, think about all the different things – what would you say, is the next worst pain? CHILD: Well, it’s all pretty bad, but … (thinking) … Of course, when
they twist my legs, that’s tough, and when they put that tube in there. Stick it up my bottom, that feels real awful (referring to catheterizing). They touch, and feel around, and put that cream there, that’s not so nice either. R-L: Quite. Do they give you any painkillers? CHILD: Yeah, I get them, but I haven’t …

R-L: So, then, what’s the least painful? CHILD: That’s when Mom and Dad take...when I’ve been in the shower, and Mom and Dad come, that calms me down. R-L: Right, sure.

R-L: What’s there that doesn’t hurt at all? CHILD: What? R-L: What doesn’t hurt at all? CHILD: Hmm, the shots, I guess. R-L: Where have they been putting the shots? CHILD: All over. The fingertips, they are sensitive, that hurts sometimes. When they haven’t been pricking my fingers, then they are ok, mostly. R-L: Quite.

R-L: I’m sure you know, because you’ve burnt yourself, because this accident happened, what the pain is like? CHILD: Huh? R-L: Can you tell what it’s like, the pain? CHILD: That’s like … that’s like… I don’t really … that really worries me. (At this point, the interview was interrupted when the nursing staff took her to the shower.)

R-L: I’d like to continue a little while still with this interview. Can you explain to me what the pain is like? Like, if I didn’t know what pain was, if I’d never felt pain, how would you describe it to me? CHILD: Mmmmh … (thinking) (There’s an alarm from the drip, and the bottle is changed). R-L: Let’s get back to that pain, what is it like? CHILD: It’s like, like when you have a wound and you touch it. When there’s that stinging sensation and then … (pause) … like when salt or something like that, so that it really starts hurting – I can’t really explain about the pain. It’s like … when it feels all shaky and jumpy. It’s like I have to shake my legs because they hurt so bad.

R-L: Hmmn. Right. And how do you feel the pain - when it hurts? CHILD: It itches. As if it was breathing, as if my legs are breathing. (indistinct speech). They’re a bit stiff. R-L: Right. CHILD: As if the pain was making them stiff … R-L: How did that feel just now, when they showered your legs? CHILD: It hurt, for sure, and then with my bottom, when they touch the skin with those swabs, with the gauze, that was real awful. R-L: What was the pain like? CHILD: It stings. R-L: It stings? CHILD: Yeah.
R-L: Right. So, listen, what do you do when you feel the pain? What helps you to manage when there is the pain? CHILD: When my Mommy hugs me and they give me something to drink, water or so. When Mommy or Daddy is with me and my sister.

R-L: Right. And is there something you can do to help yourself, when there isn’t anyone near? CHILD: Sometimes I bite the leg of that Moomin over there. That helps. It feels like it helps. R-L: Right. You’ve got good ideas about how to try to manage with the pain.

R-L: What can others do to help you? CHILD: You mean me or others? R-L: Just so. CHILD: Hmm, I don’t know, if they can help that much. A little, yes … There isn’t anybody close who can do all these things. R-L: Hm. Can the nurses help? CHILD: Sure, they can, like when they put their arm round me, or take my hand. But when they are those tough ones, they can’t help. They think … those who know how to explain everything, so that the child thinks that it won’t be so bad – but then it hurts anyway. That’s not helping. Though, maybe it’s a little comforting?

R-L: I’d like to ask you this question: why is there pain? CHILD: Yeah? R-L: Well, we all understand that pain is a nasty thing, a bad thing, but is there some benefit as well? Is there something positive about it? CHILD: I dunno. Maybe sometimes it’s a good thing, the pain. Like when … when there are places that hurt, like your belly, then you can have, like, a massage. There can be something good with the pain, too, but not with such bloody things, such bloody wounds or … like something … like something that you can’t put a bandage on, they’re not, I don’t remember what they are. But these bloody wounds, they are … and the drugs don’t … well, they help a little, but not much, when there are such big wounds. When they’re small, water and a band-aid help. Or a salve for the spots. R-L: Right.
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HOSPITALIZED CHILDREN AS SOCIAL ACTORS IN THE ASSESSMENT AND MANAGEMENT OF THEIR PAIN

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