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**UNCOVERING PAIN AND CARING FOR CHILDREN
IN THE PEDIATRIC INTENSIVE CARE UNIT –
NURSES' CLINICAL APPROACH AND PARENT'S
PERSPECTIVE**

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“The soul is healed by being with children.”

Fyodor Dostoyevsky

ABSTRACT

Background: The thesis has a standpoint in a synthesis of caring science and education science from a clinical perspective. Children in a Pediatric Intensive Care Unit (PICU) are in an exposed position, dependent on nurses to acknowledge their needs. The alleviation of children's pain has been investigated from various perspectives, but undertreated pain remains a problem in the PICU. There is a preponderance of empirical evidence pointing toward the role of nurses in uncovering children's pain and suffering. How nurses interpret the child's expressions and judge the clinical situation influences their actions in the clinical care. In a PICU, the basis for nurses' concerns and interpretation of what is meaningful in the nursing care situation are formed by professional concern, workplace culture, traditions, habits, and workplace structures. This influences how parents interpret the meaning of care as well. Patricia Benner's theory on clinical judgment forms a reference framework for this thesis. The assumption is that children need to be approached from a holistic perspective in the caring situation in order to acknowledge their caring needs. A nurse's clinical education and insights allow for the possibility to enhance the quality of care for children and parents in the PICU.

Aim: To uncover clinical concerns, from caring and learning perspectives, in caring for children in the Pediatric Intensive Care Unit (PICU) from nurses and parents perspective.

Methods: Qualitative methods were used in all studies to unfold and explore the phenomena in the nurses' and parents' everyday clinical life world. In **Papers I and II**, a phenomenographic method was adopted. In **Papers III and IV**, an interpretive phenomenological approach was adopted.

Findings: Nurses that have a holistic view of the child and approach the child from a multidimensional perspective, with a focus on the individual child and his/hers caring needs, develop a clinical "connoisseurship" and meet the parents' expectations of the meaning of care. The nurses express that it is only when they focus on the child that subtle signs of pain are revealed. The meaning of nursing care, in the ideal case, is a holistic care where all aspects are integrated and the child as a person has first priority.

Conclusion: The meaning of caring and children's needs must become elucidated to improve the cultural influence of what can be seen as good nursing care within the PICU.

Keywords: Nursing care, clinical judgment, pain, non-verbal children, PICU, caring culture, parental perspectives

LIST OF PUBLICATIONS

- I Mattsson, J., Forsner, M., & Arman, M. (2011). Uncovering pain in critically ill non-verbal children: Nurses' clinical experiences in the paediatric intensive care unit. *Journal of Child Health Care*, 15(3), 187-198.
- II Mattsson, J., Forsner, M., Castrén, M., & Arman, M. (2011). Clinical judgment of pain in non-verbal children at the Pediatric Intensive Care Unit - a phenomenographic study. *Journal of Palliative Care & Medicine*. 1(1) (open access).
- III Mattsson, J., Forsner, M., Castrén, M., & Arman, M. (2012). Caring for children in PICU, an observation study focusing on nurses' concerns. *In press, Nursing Ethics*.
- IV Mattsson, J., Arman, M., Castrén, M., & Forsner, M. (2012). Meaning of caring in PICU from the perspectives of parents. A qualitative study. *Manuscript*.

The papers are referred to in the text by their Roman numerals (I-IV).

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LIST OF ABBREVIATIONS

IASP International Association for the Study of Pain

PICU Pediatric Intensive Care Unit

RN Registered Nurse

1 INTRODUCTION

Suddenly the child became ill, requiring care beyond the ordinary. The parents lost their footing in life and followed their vulnerable and frightened child to the Pediatric Intensive Care Unit (PICU). A strange place where the parents experienced that everything happens in the present, and the perspective for the future is only a few hours. Here, everyone experiences the balance between life and death (*Material from interviews with participants within this study*).

Benner (2003) pointed out that the deepest motif of caring is avoidance of pain and alleviation of suffering. However, Ramelet et al. (2004) suggest that nurses and pediatricians have insufficient knowledge about the ways in which severe illness affects children's expressions. Furthermore, it has been found that PICU hospitalized children suffer from negative psychological sequelae (a pathological condition resulting from a disease, injury, or other trauma) up to one year after discharge, encompassing anxiety, fears, low self-esteem and self-confidence (Rennick & Rashotte, 2009). To care for a silent patient and his or her family presents particular challenges according to Benner et al. (2002), as the PICU environment might become an obstacle for families to involve themselves with the child during the PICU admittance (Frazier et al., 2010). On the other hand, when parents can be engaged in caring, it decreases their helplessness and anxiety (Harbaugh et al., 2004). For children, to suffer from pain is among their greatest fears (Brady, 2009; Carter, 2004; Foster, 2001). Yet, critically ill pediatric patients are frequently exposed to acute, established, and chronic pain as a result of their disease processes or intensive care therapies (Brady, 2009; Stevens et al., 2009). Several studies reveal shortcomings in the pain assessment for severely ill children, who are not getting adequate pain alleviation even though both the means and methods exist (Bennett, 2001a, 2001b; Cheng et al., 2003; Franck et al., 2009; Manworren, 2007; Manworren, 2000; Simons et al., 2009). In line with these studies Stevens et al. (2009) assert that physicians and nurses occasionally lack knowledge of how to interpret expressions of pain in children with special needs.

2 BACKGROUND

The following section presents a paradigm case that is meant to highlight different aspects of the complex pain alleviation faced by the nurses in their everyday clinical work in the PICU. Pursuant to the phenomenological tradition set forth by Benner et al., paradigm cases serve to enlighten lived phenomena in their full context (Benner et al., 2009). Although the case as a whole is not authentic, it is in its parts because it is based on material from interviews and observations with participants within this study. The description should be considered as an example of what the PICU nurses attend to in their everyday clinical practice.

Hubert, almost four years of age, lies in a large hospital bed with devices all around him. He is severely ill and has been for almost two weeks. Communication with him is sparse, and his expressions are not clear. At times he has been intubated and sedated. He has severe pneumonia and lies intubated in the bed without a blanket. His father asks if he is cold. The nurse says that he has a fever and that lying with no blanket helps to normalize his temperature. Hubert's parents wonder how long this situation will go on. The nurse answers: "We don't know," adding that it might be the infection making it worse. "We're monitoring the temperature, taking tests and then we'll see." The nurse turns to Hubert and looks at him. She tries to see if he is in pain. She knows that pneumonia is painful, but does Hubert have any pain anywhere? It is not easy to judge the possible pain, how strong it is, or where it originates from because Hubert either does not want to or does not have enough energy to talk. As the nurse sets up the appropriate equipment to start an infusion, she makes small talk with Hubert and asks his mother to describe how he usually expresses his pain. The nurse looks at the monitor. She sees that the heart rate looks good, a little fast, but he has a fever. "It may be due to the fever," she thinks. Blood pressure is slightly elevated, but not so much that it suggests a lot of pain, she thinks. Something attracts her attention. Hubert's fingers are picking and fidgeting with the sheet continuously, moving back and forth. His feet are moving lightly and he seems a little worried. He utters small coughs occasionally, short and hard, maybe a little too short. Breathing is shallow and he takes a few deep breaths. The respirator signals, his eyes are half open. "Is it pain, anxiety, or both?"

She walks over and puts her hand on Hubert's cheek, as she speaks reassuringly to

him. She notices a tension over the bridge of his nose, which wrinkles the skin in a small pleat, something that she does not usually see when he is relaxed and comfortable; she feels Hubert's body and looks at his posture. He feels a little too tense, as if he is lying on top of the sheets and not sunken down comfortably into the mattress. The tension she feels in her hand is a little too tight to be relaxed, but not so tight that it offers a resistance. She has felt the tension many times before, and experiences it as a sign of pain. She tries to turn Hubert to see if she can get him into a more comfortable position.

Hubert does not say anything, but moans a little more during exhalation than he usually does, when it just becomes uncomfortable. The groan lasts a little too long for her to ignore it. He does not relax afterwards and does not appear to be calm despite her attempts to prop him up with pillows and relieve his body from pressure. The toes remain a bit tense, and it does not seem really good. She weighs all these tiny signals together. There are many different small characteristics in the situation when she gives nursing care that leads her to the decision that Hubert is in pain.

It is not easy to uncover pain; she believes that there is not a good pain assessment instrument for children who also have to undergo intensive care sedation. She trusts her experience and gives Hubert prescribed morphine when necessary. Soon, he has calmed down, takes deep breaths and sleeps well. The heart rate and blood pressure have decreased, saturation has increased and the cough is becoming deeper, stronger, and longer. The conclusion drawn is that he was in pain and that she acted appropriately in the situation.

2.1 THEORETICAL FRAMEWORK

This thesis has a theoretical standpoint in both caring science and educational science from a clinical perspective, and the above example gives a sense of the complexity occurring in clinical situations. In the encounter between the child and the nurse, it is not just about two persons meeting, it is also about the two persons interwoven lifeworlds. However, they might differ regarding what they find meaningful in the situation as well as how they experience it. Benner and Wrubel (1989) stress the importance of a theory that supports descriptions and interpretations, and explain actual nursing as it occurs in day-to-day practice and not as an imagined ideal nursing. Guba

(1981) highlights that a basis for naturalistic inquiry is the importance of studying the empirical world from the viewpoint of the persons under study, with regard to the influence of the physical, sociocultural, and psychological environment on the behavior. Benner et al. (2009) express that individuals within their own context allow us to capture the essence of lived experience as they are brought to light through the experience of individuals.

Benner (1994) and Benner et al. (2009) argue that humans beings experience of their world and the everyday existence is the core of the lifeworld theory. A theory that has its standpoint in phenomenological philosophy and includes a non-reductionistic and integrative view of life and world, body and soul, object and subject, a non-dualistic view (Ahlberg, 1997; Marton & Booth, 1997). Ahlberg (1997) and Marton and Booth (1997) argue that people perceive their physical, social, and cultural world as they live in it. The world is a whole and cannot be considered separately. According to Marton and Booth (1997, p. 30), there is no real world out there and no subjective world in here. They add, "The world is constituted as an internal relation between them. There is only one world, but it is a world that we experience, a world in which we live, a world that is ours." The basis for the relationship to the world is the human activity. According to Marton and Booth (1997), our consciousness bestows a meaning in every situation. Benner et al. (2009) claim that caring is a basic way of being, that is, as we are involved, things become evident and thus become important to us.

The epistemological assumptions on which the thesis rests on is that theoretical, practical, and experiential knowledge are equal and important sides of knowledge. Furthermore, these are of importance for the advancement of the nursing profession. Benner et al. (2009) argue that experiential and empirical knowledge gained in clinical practice precedes theoretical knowledge, which needs to become incorporated in science to become theoretical. According to Lundborg (2005), there is a difficulty in distinguishing between theoretical and practical knowledge in a more simpler or clearer way, since both forms unite in practical knowledge and in acting. Hedin and Svensson (1997, p. 12) state that theoretical and practical knowledge presuppose each other and can thus be seen as two sides of the same coin. They believe that a gradual process occurs from daily practical duties via theoretical analysis of what is known. Consequently, this results in new knowledge. According to Hörberg et al. (2011), learning strategies that facilitate an encounter between scientific knowledge and lived reality is required in caring science to meet the lifeworlds complexity. Caring and

learning are intertwined and inseparable from life; accordingly, a lifeworld based approach is beneficial, to develop strategies to strengthen learning processes as well as a persons health. In this paper, individual knowledge is seen as an activity manifested, as suggested by Marton (1981), when a change has occurred in the perception of a phenomena, allowing for a new understanding to be developed.

Theoretical knowledge is described as an empirical, systematized form of knowledge extracted from standard scientific methods; it is general, reflective, and critically collated; it describes that something is a certain way. Theoretical knowledge is strongly selective and can describe only fragments of reality (Pörn, 1990). Moreover, theoretical knowledge can be divided into factual knowledge, asserted knowledge, and comprehension.

Practical knowledge is often described as referring to something involving intervention, for example, the application of a skill within a field, while theoretical knowledge is described as referring to an observation or reflection on something. Pörn (1990) believes, however, that a division into theoretical and practical knowledge is unfortunate since the two cannot be separated. Thomassen (2007) also believes that these forms of knowledge are mutually dependent, and that they meet in experience. Pörn (1990) calls the knowledge in knowing what something means *comprehension*, and says that it also involves understanding how things connect and when this is useful. These three kinds of knowledge are mutually dependent and basic for how human knowledge is organized. Practical knowledge also includes the concept of *skills knowledge*, which involves a capacity to draw conclusions from basic data in the clinical work that lead to intervention and the ability to support the choices and judgments (Thomassen, 2007).

Experiential knowledge is knowledge acquired through direct personal experience of a phenomenon or occurrence, and involving the integration of the above-mentioned forms of knowledge with that personal experience. Benner (1982) and Benner and Wrubel (1989) do not distinguish between practical and experiential knowledge, seeing them instead as unified. They consider that experiential knowledge develops through practice and builds on a personal perception of a context-based situation. Kolb (1984) describes the experiential learning process as a cycle containing concrete experience, reflective observation, abstract conceptualization, and active experimentation.

Bengtsson (1993) submits that experiential knowledge is a form of theoretical knowledge because experiential knowledge develops through reflection, either alone or with others. Högberg et al. (2011) assert that the transformation from caring science to practice means to reflect. The subjective lived knowledge becomes reflected against caring science knowledge and practical knowledge and allows the person to intertwine knowledge and gain a new and deeper understanding. Mor and Winters (2007) argue that we need to attend to the development of learning to increase the quality in our capacity to solve problems.

2.2 NURSING CARE AND CARING

Nursing care and caring is understood from the previous works of Patricia Benner and her co-authors. Benner et al. (2009) and Benner and Wrubel (1989) claim that the nature of caring in the nursing profession is shaped by situations, relationships, and patients, which in turn shape our practice and understanding. Nursing care contains the aspects of a situation, the attributes of a situation, and competence involved in a situation from interaction with the patient. Spichiger et al. (2005) emphasize that caring is to care, which in turn is to interpret what matters. Caring makes people direct their conscious toward whom or what they care for, and how help is given or received. To care from a lifeworld perspective means, according to Benner (2003), Benner and Wrubel (1989), and Benner et al. (2009), to have a holistic view of the patient that involves alleviation of pain, avoidance of suffering as well as promotion of safety, growth, and health. Nursing care also includes the alleviation of vulnerability, the facilitation of comfort, dignity, or a good and peaceful death (Benner & Wrubel, 1989; Benner, et al., 2009). Spichiger et al. (2005) view the nursing care as located in a specific lifeworld, which is culturally influenced and as such shapes the persons concerns and structure of the care given. Marton and Booth (1997) stress that when we experience something our consciousness is directed toward this intentional object. The basis for the direction of consciousness consists of the knowledge and experience we possess. How something is experienced is not related to a specific experience, but dependent on the accumulated experience and how one perceives something here and now. Benner (1994) points out that caring is characterized by the room and time (temporality) movement between the present, past, and the future. The meaning of caring can be viewed through nurses' concerns in the caring situation, which are intentional and emerges from the daily everyday life in all

its variety. Therefore, the development of knowledge with regard to these aspects is of great interest for the science as well as for care giving professionals.

2.3 CULTURE AND CARE

The caring culture studied by Rytterström et al. (2009) similarly reflects the climate of the group, caring attitudes, and actions taken based on the unwritten routines and rules that form the workplace culture. Culture is in this view a creation of common meaning and is dependent on factors, such as tradition (organization) and horizon (current knowledge and what is considered important). However, as pointed out by Roxå et al. (2011), some individuals have access to more information than others since they are more central; accordingly, they also have access to discussions where meaning is negotiated. This might have implications for how the culture in healthcare is organized, and what aspects are determined as being important to learn in the organization.

The culture in a workplace can be viewed as an important factor in the understanding of how the nursing care is applied and how co-workers construct meaning together. The culture in the workplace constructs meaning and is recognized, by Latham et al. (2008) and McNamara et al. (2011), as an important factor for nurses' retention or engagement.

Berger and Luckman (1996) claim that people construct meaning as they engage with the world in their everyday lives. They further assert that culture can be viewed as a set of guidelines, explicit and implicit, which individuals as inherent members of a society use to guide them to view the world, experience it emotionally and learn how to behave in it (Helman, 1994). According to Trowler (2009), people are socialized into a certain way of viewing things. For instance, the epistemological underpinnings represent a key driving force of understanding and deciding what is important as proposed by Bolander Laksov et al. (2008), especially given that the management team of hospital wards are often represented mainly by physicians. The physicians might have the last say in what is important, right or wrong, on a cultural basis. Benner et al. (2009) describe a complex pattern of collaboration between nurses and physicians, which mainly supports the dominance of the physician and subordination of the nurses. This implies that there might be limitations for the nurses or others in the community that define or contribute to the "common values." In this perspective, the physicians can be viewed as

being the gatekeepers of the practice and the “true” cultural bearers. In clinical practice, this might have implications for how nurses view and implement their own nursing care. In Trowlers (2009) words, the physicians represent the hard, pure convergent and urban dimension that are to co-exist with the nursing profession that is softer, applied divergent and rural. The still unclear question is to comprehend the creation of concerns and meaning-making in a clinical care culture such as the PICU.

2.4 CONTEXT OF THE RESEARCH AREA

According to Lindblad-Fridh (2003), the PICU in Sweden has its own context, its own “language,” and its own treatment culture. A PICU is limited to the hospital’s critically ill patients. Beds are exclusively for technical treatment, which means that patients under care are all formally registered with another hospital department. Intensive care involves treatment or monitoring of latent or manifest failure of vital functions. This presumes that the acute cause for the condition is temporary or eliminable (Eklund et al., 1987). Lindblad-Fridh (2003) asserts that intensive care of children is a specific problem area demanding specific pharmacological, physiological, and development-psychological expertise from various staff members as well as a capacity to cooperate with children and parents in the special environment.

2.5 CHILDREN IN THE PICU: HIGH RISK OF SUFFERING

Children that are cared for within the PICU are severely ill, often admitted due to multiple organ dysfunctions. The care in a PICU differs from other realms of pediatric care in the acuity of the care and the higher possibility of the admission ending in the death of the child (Ramnaryan et al., 2007). In addition, the PICU care has been shown to render psychological suffering as well as delusional memories in children after discharge (Rennick & Rashotte, 2009; Colville et al., 2008).

For the parents, it is stressful to have their child admitted to a PICU (Board et al., 2002; McDonald et al., 2012). Most stressful, according to Miles et al. (1989), was seeing one’s child in pain, frightened and sad, experiencing the child’s inability to communicate, and the feeling of being unable to protect the child, that is, not knowing how to best help the child.

When cared for at the PICU, children are exposed to a variety of potential suffering as well as painful situations and tests. According to the IASP (the International Association for the Study of Pain), pain is defined and described as being an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage (International Association for the Study of Pain, www.iasp-pain.org. Sourced 2012-05-09)(IASP, 2005). The IASP defines pain as a sensory and emotional experience, always subjective, but it might not always be expressible.

Bennett (2001a) points out that children on ventilators suffering from serious illnesses or those medicated with sedatives need special attention from the nurse, who is able to recognize and treat acute pain. The use of inotropic, chronotropic, and other vasoactive drugs often influence the child's physiological variables; in addition, during prolonged pain episodes these variables tend to return to the child's personal baseline (van Dijk et al., 2005). Furthermore, the use of opiates and benzodiazepines are associated with children's memories of nightmares, hallucinations, or a sense of someone trying to hurt them (Colville et al., 2008).

The alleviation of suffering is the most important part of a nurse's responsibility (Benner et al., 2009). However nurses expresses difficulties in assessing pain in younger children (Gimble-Berglund et al., 2008). Children who cannot verbally express themselves are exposed to various levels of suffering. Since they are assessed by how they act, specialized knowledge is required from professionals. In a study by Byrne et al. (2001), nurses interpreted children's communications of pain as unreal and unwarranted. It was found that they were trying to prevent children from displaying expressions and behaviors deriving from pain. In a study by Gimble-Berglund et al., (2008) nurses' were found to be ignorant towards procedural pain. These are examples of how caregivers fail to interpret or to give credibility to the child's suffering from pain. There is a considerable risk of under-treating the child's pain if pain alleviation is guided by intuition and myth rather than evidence-based knowledge (Simons & Moseley, 2009; Versloot & Craig, 2009).

The ability of a child to express experiences develops with age. Thus, children's behavior changes in relation to pain experiences; moreover, boys and girls may differ in how they communicate and behave when it comes to pain (McGrath, 2005; McGrath, 1995; Miller et al., 2001). Koutanji et al. (1999) indicate differences between age

groups and how they verbally communicate pain. Younger children use words that describe sensory experiences and evaluate them as “great or little hurt,” while older children describe with more detail as well as how pain affects them. Girls articulate pain using expressive words earlier than boys. It is highly probable that adapting to pain affects a child’s behavior (Twycross et al., 2009). During the hospital treatment period, nurses are responsible for the regular alleviation and evaluation of a child’s suffering. To be able to alleviate a child’s suffering from pain, nurses are responsible for both pharmacotherapeutic and non-pharmacotherapeutic methods of alleviating pain. Generally, non-pharmacotherapeutic measures such as touch, shifting position, and changing sheets depend on the nurse’s judgment, which depends on communication of some expression of pain from the child. Much of the communication between severely ill children in the PICU and the nurses is non-verbal. Nurses judge which signs to interpret as pain and how the signs are categorized and prioritized. This judgment is part of the capacity nurses must possess to understand a patient’s pain as well as the inconvenience the pain is causing the individual patient.

2.6 PROBLEM AND ASSUMPTIONS

The children under the care of the nurses in this research were severely ill and admitted to the PICU. Whatever the reason bringing the children to the PICU, once there, they are subjected to suffering and many potentially painful procedures. The perception of a child’s suffering and pain is a complex task in the PICU, which is related to the complex interaction in the caring situation. Benner et al. (2009) argues that to develop experience-based knowledge, the individual must also achieve awareness of a situation’s complexity and that other actors should also see and understand the situation from other perspectives. For nurses implementing pain alleviation and for children who risk pain, it is important that knowledge of the factors underpinning pain alleviation is properly considered and analyzed.

If nurses do not know or recognize expressions of suffering from the vulnerable child, the child not only is at risk of feeling pain, but also of having the healing process prolonged or developing long-term problems (Ramelet et al., 2004). To recognize and take action to alleviate suffering Söderbäck et al. (2011) argue that the child should be invited to participate according to his/her ability. Which can be a subtle process in the PICU where the severity of the child’s condition might obstruct the child’s ability to

express pain Which highlights the importance of judging and learning about pain and how it can be interpreted in a certain context.

There have been efforts to understand how the clinical learning develops and what it constitutes; however, the full picture and the consequences for the child still remain unclear. Benner et al. (2009) argue that in order to be able to see the patient, to get to know the patient, and become fine-tuned to the patient's special needs, we need to become engaged. However, the engagement from the nurse may be of diverse origin, elucidating different aspects in the nursing care. This means that the patient's needs could become more or less addressed. What's more, children express that their parents are very important to them (Van Sta et al., 2011) because they are relying on them to look out for them. In a PICU context, parents might experience themselves as being alienated from their child (McDonald et al., 2012). Söderbäck et al. (2011) argue that to truly become child centered, it requires that the adult perceive and understand the child's world, inviting the child to participate according to his/her ability. However, How to counteract such feelings and strengthen the child-parent relationship is of importance, both for the child and the parent as well as the nurse. To develop knowledge in nurses caring for children in the PICU with an emphasis on aspects in nurses' learning and their alleviation of children's suffering, it is important to unfold issues concerning the nurse's and parent's world, that is, what is it like to be a nurse or a parent in the PICU, what is it like to care for children with illnesses and suffering. How does this influence their care given? Subsequently, it is of interest to search for a deeper understanding of caring for children in the PICU in order to develop an optimal care.

3 AIM OF THE THESIS

To uncover clinical concerns, from caring and learning perspectives, in caring for children in the Pediatric Intensive Care Unit (PICU) from nurses and parents perspective.

3.1 SPECIFIC AIMS, PAPERS I-IV

To illuminate clinical experiences of pain in the PICU; describing nurses' perceptions of expressions of pain in non-verbal critically ill 2–6 year old children (I).

To explore nurses' perspectives (i.e., their expressed experience, opinions) on clinical judgment of pain in critically ill non-verbal children in the PICU (II).

To unfold the meaning of nursing care through nurses' concerns when caring for children in the PICU (III).

To investigate the meaning of caring in the PICU from the perspective of parents (IV).

4 OVERVIEW OF METHODS

4.1 OVERALL STUDY DESIGN

This thesis comprises four studies, using the qualitative approach, all carried out within the PICU context in Sweden (Fig. 1). The studies explore the PICU as a lived space from both the nurses' and parents' perspective. Qualitative methods were used to unfold and explore phenomena in the PICU uncovering the given meaning of the experience from the perspective of those being studied (*cf.* Benner, 1994; Benner et al., 2009).

4.2 PARTICIPANTS AND DATA COLLECTION

Since human experiences were sought, purposive sampling was chosen for the thesis as a whole (Fig. 1). The first data collection (Papers I and II) took place in a PICU in the middle of Sweden. The criterion for participation in the study was: a nurse's qualification with specialist training in intensive care or anesthesia, or specialist training as a pediatric nurse. Having experience in children's hospital care was also mandatory. The respondent group consisted of 17 qualified nurses, thirteen female and four male. The respondents had specialist training as nurses in intensive care, further training and qualification as anesthesia/intensive care nurses or pediatric nurses. All those interviewed were working as qualified nurses. The number of years of nursing experience varied between five and 32 years with a median of 14. Specific experience of children's intensive wards varied between three months and 28 years with a median of 4.5. All had previous experience in medical care of children. Data were collected through interviews with support from an interview guide. Between January 2004 and June 2004, ten interviews were conducted during daytime (Papers I and II). To maximize the variation, an additional seven interviews were conducted at nighttime between May 2005 and June 2005.

The findings in Papers I and II guided the second, broadened data collection (Papers III and IV) that comprised all PICUs in Sweden. The data collection concerned the whole situation with the child, family, and siblings, and was performed between March and June 2011 and embraces all PICUs (N=3). A total of thirty-three specialist nurses (thirty women and three men) participated in the observations and a total of thirty nurses were interviewed (twenty-seven women and three men). Three women did not

participate in the interview due to the severity of the child's condition, which inhibited them from leaving the child to participate in the interview. Thus, they were excluded from the study. The selection was done by purposeful sampling of those nurses in the settings that were a specialist nurse and who agreed to participation in an observation and following interview. Data were collected until the researcher found the data to be rich and detailed. All participants had specialist training in intensive care, pediatrics, anesthesia, or the older form of advanced training that rendered competence within both anesthesia and intensive care. Their PICU experience varied between three weeks and thirty-seven years. For Paper IV, the data collection comprised all PICUs in Sweden (N=3), and was performed between March and June 2011. Eleven parents, seven mothers and four fathers, of seven children presently undergoing treatment in the PICU were included in the study. The children were between newborn and seven years of age, two were girls and five were boys. The selection of parents was done by consecutive sampling of those parents in the settings that agreed to participate in an observation and following interview about the care from their perspective as a parent to a child admitted to the PICU. All parents that were approached agreed to participate. All children were treated for severe life threatening conditions.

4.3 INTERVIEWS

The purpose of the interviews was to capture the participants' views within the question areas (Papers I-IV). All interviews were tape-recorded and transcribed verbatim. Lantz (1993) believes that the interviewer and the interviewee are not on equal footing, since the interviewer is the dominant person, asking questions and following up on that which is of interest to the interviewer. In contrast, Marton and Booth (1997) argue that the power lies within the respondent, as he or she can choose to answer the questions or not in any way he or she wants. In the interview situation, the interviewer tried to take into consideration both these scenarios. Firstly, the respondents took part in the interviews voluntarily but even if the interviews were based on voluntarism, there were aspects that needed to be considered. Secondly, the interviewer informed the respondents that he/she could cease the interview at anytime with no questions asked, if that was what he/she wanted to do. Thirdly, the interviewer tried to create an open atmosphere during the interview, giving the respondent room to express themselves as they pleased and not feeling pressured in any direction. Fourthly, in the study interviews, the interviewer encouraged the respondents to talk as fully as possible about

their ideas and experiences. It was also important to listen to the subtext, that is, to discover what was latent and ask for confirmation or clarification of the interviewer's interpretation of the respondents' statements. The data collection attempted to capture as many nuances and descriptions as possible relating to the specific study area (*cf.* Marton & Booth, 1997). The interviews in the first data collection followed the path described by Linder (1999), beginning with a predetermined question of an open nature, then following a semi structured interview guide to ensure that the study area was covered (Papers I and II). The semi structured interview guide in the subsequent data collection contained questions influenced by Benner and Wrubel (1989) and Benner et al., (2009) (Papers III and IV). The following themes were discussed: Emotional involvement, problem engagement, environmental hindrances, environmental facilitating, and significant networks (Papers III and IV).

The respondent was given enough time to ensure mutual understanding of the questions and to get exhaustive information of how they understood the phenomenon (Holloway & Wheeler, 1996; Larsson, 1986). Each interview was 20–60 minutes long, starting with an open-ended question and aimed to capture each respondent's unique personal and specific experience. The meaning of the perception of the studied phenomenon can change depending on the context, language, culture, and everyday life in which the respondent meets the phenomenon (Theman, 1983). It was also important to find the latent information and substantiate it by reversing an interpretation and asking the respondent for confirmation (Marton & Booth, 1997). By striving for a climate of transparency, the participants were given the opportunity to delineate and define the content. The interviewer was attentive both to what was said and to how it was said. Answers were followed up with questions such as “how?” and “can you elaborate?” All the interviews were conducted at the PICU and transcribed verbatim by the first author (J.M.).

4.4 OBSERVATIONS

The other data collection method (Papers III and IV) was expanded with observations N=30 (Paper III) and N=7 (Paper IV) to gain access to the lived experience. The observations were conducted bedside and field notes were written. The observations were 120–240 minutes long. Benner et al. (2009) emphasize that how nurses function in the caring situation is more evident in observations than in narratives thanks to the possibility to see how the everyday act occurs. The observer (J.M.) tried to understand

the nurses' central concerns for the vulnerable children, their concerns in the caring situation, how they organized nursing care, and worked in the situation (Paper III). Furthermore the observation took in the parents' situation when they were present (Paper IV). Observations were used to highlight situations in the subsequent interviews. According to Benner (1994), those things that are taken for granted will not be reflected upon until something out of the ordinary happens. Brykczynski and Benner (2010) also argue that through observation, what is happening is made evident in a clear manner.

In Papers III and IV, observations and semi structured interviews were combined as observations, with a validating interview (Benner et al., 2009; Spichiger et al., 2005). The validating interviews in Paper III (N=30) were recorded after the observation at the workplace in a separate room. The intention was to capture the meaning of the nurses' experience of the nursing care situation that previously had been observed. The participants were asked to describe their experiences, thoughts, and feelings about the nursing care that had occurred previous to the interview. Although it is not common to use an interview guide in phenomenology, in this study one with thematic questions influenced by Benner and Wrubel (1989) and Benner et al. (2009) was used to support the nurses in telling their story. After the nurses' own narrative about the caring situation, the thematic interview guide was used to discuss the following themes: Emotional involvement, problem engagement, environmental hindrances, and environmental facilitating.

For study IV (N 11), seven mothers and four fathers, of seven children presently undergoing treatment in the PICU were interviewed. All interviews, with one exception, were recorded at the PICU in a separate room and later transcribed verbatim. One couple did not want to leave their child due to the child's very critical condition, but still wanted to share their experience. In this situation, notes were taken. The intention with these interviews was to capture the parents' experience of the meaning of care during their stay at the PICU. The parents were asked to describe their own unique experiences, thoughts, and feelings about being a parent to a severely ill child. It was the role of the interviewer to allow the parents to tell their stories in personal, emotion-filled terms, and at the same time slowing the pace of the interviews so that details would not be lost (*cf.* Benner et al., 2009). Follow-up questions and probes were used to further explore salient and relevant issues raised by the parents. An interview guide with thematic questions influenced by Benner and Wrubel (1989) and Benner et al. (2009) was used, and the following themes were

discussed: emotional involvement; problem engagement; environmental hinders; environmental facilitating.

4.5 THE EMPIRICAL MATERIAL

The thesis is based on material from two sources, interviews and observations, as described above. The interviews were tape recorded and transcribed verbatim into Swedish by the first author. After the transcription, the written text was checked for accuracy and compared with the taped interviews. The written text was corrected accordingly to the interviews, if needed. The field notes taken during the observations were also written in Swedish. However, in Papers III and IV, the observations and interviews were combined. The materials were analyzed with different methods for the four papers included in this thesis. Interviews from only one PICU was used for Papers I and II. For Papers III and IV, national interviews and observation material from PICUs in Sweden were used. During the analysis the first author listened to interview recordings and re-read observational notes several times.

5 METHOD

In this thesis, two different methodological approaches have been used. They are as follows: a phenomenographic method and an interpretive phenomenological method. The reason for this was to show the nurses' everyday life and experiences in the clinical ward from different perspectives that could help to uncover patterns in nursing care, which could contribute to the understanding of the complexity of pain alleviation in the PICU. Firstly, a phenomenographic approach was chosen to uncover how nurses experience children's expressions of pain and judge pain in the PICU (Papers I and II) since this was poorly covered within previous research (Ramelet et al., 2004). Phenomenography was deemed suitable for answering this question since it is a research approach designed to answer questions about how people make sense of their experience. It also discerns and describes qualitatively different ways of perceiving phenomena in the surrounding world (Marton, 1981; Marton & Booth, 1997). To experience something, people have to discern its structural and referential aspects. This means that they discern something from its context and how this part is linked to the whole, which is linked to the referential aspect. When people see both the parts and the whole of something, they understand the meaning (Marton & Booth, 1997). A phenomenon can be described from two perspectives: In the first-order perspective, the interest lies within how something really is. In the second-order perspective, the interest primarily focuses on how phenomena are perceived. How people perceive the specific situation depends on the qualitatively different ways in which various phenomena, and aspects of the world around them are experienced, conceptualized, understood, perceived, and comprehended. The focus for the phenomenographic approach is the second-order perspective, in order to obtain qualitatively different conceptions of an existing phenomenon within a population, and then to describe these differences (Marton, 1981; Sjöström & Dahlgren, 2002).

To uncover how nurses lived their clinical situation, an interpretive phenomenology method as described by Benner (1994), Brykczynski and Benner (2010), and Benner et al. (2009) was adopted in Paper III. In Paper IV, an interpretive phenomenological method as described by Benner et al. (2009) and Brykczynski and Benner (2010) was adopted to articulate aspects of caring in the PICU from the parent's perspective. The purpose of interpretive phenomenology is to study human beings from within their lifeworld, in their own context, in order to uncover and highlight qualitative aspects of

practice embedded in the caring situation (Brykczynski & Benner, 2010), as they are brought to light through the experience of individuals (Benner et al., 2009). The research process (Paper III) was guided by Benner and Wrubel (1989) and Benner's (1994) description of commonalities. Commonalities can be viewed as addressing a structure of what is shared as a common understanding of a nursing care situation, but it is how commonalities are performed in the nursing care situation that can be understood as constituting the meaning of care. The commonalities are as follows: *Situation*, which addresses the nurses' understanding and relationship to the situation and in the situation. *Embodiment*, which addresses the embodied knowing that allows nurses to respond in a meaningful situation. *Temporality*, which addresses the experience of the lived situation. *Concerns*, which address the way the nurses are oriented meaningfully in the situation. All these commonalities have been taken into consideration in the research and analysis with an emphasis in the presentation and discussion on concerns. Paper IV was divided into two interconnected parts, that is, observations and interviews. The purpose of the observations was to capture the situatedness via close observations of direct practice with children and their parents. The purpose of the parent interviews was to explore their view of caring in the PICU. Benner et al. (2009) argue that if the basic way of being in the context is sought, the method of the study must try to access the structure of activity as it progresses. She also asserts that qualitative aspects of meaning are brought to light through the experience of individuals.

5.1 DATA ANALYSIS

5.1.1 Qualitative analysis

This thesis builds on diverse qualitative analysis. The acquisition of information builds on the relationship and dialogue between the participants and the researcher, that is, what emerged during the interviews and observations. Selected parts of the findings that emerged after the analysis were translated from Swedish into English, due to publication.

In Papers I and II, the tape-recorded and transcribed interviews were analyzed in seven steps according to a phenomenographic procedure (Larsson, 1986; Sjöström, 1995).

However, the findings are presented in different ways. In Paper I the findings were presented in a horizontal way. In Paper II the findings were presented in a hierarchical order, which means that the findings are presented with regard to levels of understanding expressed by the participants.

The Analysis was performed in collaboration with the co-authors and discussed in seminar with researchers experienced in phenomenographic analysis. The analysis was conducted as follows:

Familiarization. In this initial phase, the researcher read the transcripts of the interviews carefully several times with the aim of getting acquainted with the text in detail.

Condensation. The most significant answers from each interview were selected and reduced to significant statements. This step required awareness of the researcher's own preconceptions in order to ensure that the condensation really focused on what the participants brought to the discussion.

Comparison. All of these statements were compared to identify sources of variation or agreement.

Grouping. Statements with a similar condensed content were then assigned to groups of preliminary classification. Based on this grouping, the categories and sub-categories that would form the results were developed in the next step.

Articulating. The essence of the similarities within each group of answers was given a preliminary description, including a limited and central content for each qualitatively different and non-overlapping category.

Labeling. This step consisted of the construction of a suitable linguistic expression that captured the essence of the articulation denoted by each category, presented first in the findings.

Contrasting. In Paper I, the overall meta level was then analyzed. The categories obtained were compared with regard to similarities and differences and presented separately. In Paper II, the contrasting meant to compare the categories obtained with regard to the levels of understanding expressed by the participants at a meta level.

According to Marton and Booth, (1997), a person's qualitatively different way of experiencing a phenomenon represents a more or less comprehensive understanding of the phenomena. These differences can be ordered hierarchically in comparison with established knowledge about the phenomenon. The categories in this study were

hierarchically ordered and labeled A, B, and C, starting with the most elaborated understanding as judged by experts in the field. This “negotiating consensus” is a process performed in the phenomenographic approach to replace an inter-judge reliability test. Depending on the understanding presented, concepts with elaborated answers comprising at least three important components related to clinical judgment of pain were sorted into category A. Less elaborated concepts with two important components were labeled B, and the concept with one important component was labeled C. The first author analyzed the data, and discussed the analysis with the co-authors and experts in the phenomenographic method. Grouping and articulating were repeated several times.

In Papers III and IV, interpretive phenomenology was used in accordance with Benner, (1994), Benner et al., (2009), and Brykczynski and Benner’s (2010) suggestions of how to conduct analyses using this method.

The analysis primarily focused on the observations, and the interview text elaborated, confirmed, or contradicted this analysis. The analysis consisted of three phases, which moved back and forth between foreground and background, and between situations and the practical worlds of the participants. The analysis began in conjunction with data collection and transcription of interviews. Observations as well as transcribed interviews were read several times in order to get a preliminary understanding of what the data, as a whole, described (J.M.). An alteration between closeness and distance, reading and understanding was performed. In the second phase, data underwent an interpretive investigation where paradigm cases and exemplars were sought after in the observational data and later confirmed or rejected in the transcribed interview text (J.M., M.A., M.F.). In the third phase, a thematic analysis was conducted by bringing the identification of paradigm cases and a dialogue with the exemplars text together, resulting in preliminary themes of interpretations of nurses’ understanding of meaning in the caring situation. During the thematic analysis, parts in the observational field notes and interviews that were viewed as salient to the aim were underlined and given broad descriptive themes, aiming to understand the meaning in those underlined parts. The third phase contained a process to triangulate data and establish descriptive names for aspects of the text that the first author and the co-authors (M.F., M.A.) found as prominent to the study aim. The first author and the co-authors (M.F., M.A.) discussed the meaning that was captured by the various names. The purpose of naming was to

capture examples of patterns of meaning in action, that is, a meaning structure, including a salient context that was representative to present the findings in a true way.

In Paper IV, an interpretive phenomenological analysis was adopted, creating a dialogue between practical concerns and lived experience to study the phenomena on its own terms as suggested by Benner et al. (1999), Benner et al., (2009) and Brykczynski and Benner (2010). The analysis process contained situation-based data collected through observations and interviews. The analysis began in conjunction with the data collection. Thereafter, it continued with reading and interpretation of exemplars, comparison and contrasting, and a thematic analysis of those. Criteria for methodological rigor were applied using established methods for interpretive phenomenology (Benner et al., 1999; Benner et al., 2009). Audio- recorded interviews were verbally transcribed by the first author (J.M.) and investigative triangulation was built into the design through interpretation of the exemplars, comparison and contrasting of the written interviews done by co-authors (J.M. and M.F.), and a thematic analysis was conducted by all of the authors (J.M., M.F., M.C., and M.A.). Benner et al. (2009) argue that the thematic analysis should be done in close connection with the narratives as this brings out the meaning in the narrative. In the analysis in this study, time was spent to condense the meaning in the parents' statements and to switch between the whole and the parts several times to gain access to the meaning of the text.

5.2 TRUSTWORTHINESS

The trustworthiness is related to the understanding of the work as a whole, ranging from design, data collection, and interpretation examining the coherence toward the practical concerns that motivated the study (Brykczynski & Benner, 2010). A qualitative design and approach was chosen in order to gain an understanding of what it is like to be and act as a nurse in the PICU, and observing and interviewing was deemed to be purposeful for this quest. According to Guba (1981), the truth-value is strengthened if the phenomenon sought is made evident from various perspectives and the results are acknowledged as accurate interpretations from people that share the described experience. In this study, the design facilitates triangulation and the phenomena are sought from different perspectives. What emerged during the research process was critically reviewed and examined against other interpretations and possible

explanations as suggested by Benner (1994). It has been a strategy throughout this study to discuss what could be a reasonable interpretation with the researchers within the study and who are familiar with the material. Throughout the research process, there was a dialogue among the team involved in the data analysis (*cf.* Brykczynski & Benner, 2010). In this study the whole and parts of the interviews, observations, and research findings were discussed in general and specifically within the research group (*cf.* Benner, 1994).

Trustworthiness is also achieved via the logical structure of the study, that is, how well the design supports the aim of the study and how well the research is completed.

Throughout the process, the study has been questioned in accordance with Silverman's (2006) remark that the trustworthiness of qualitative research concerns the whole study.

The applicability (Guba, 1981) refers to the degree to which the findings in the study can be applied to other contexts, outside of the study. Even though the results in this study are limited, it is reasonable to believe that the results may be applicable and transferable to similar situations and contexts. The strength of the qualitative methods used in this study is that they are conducted in a naturalistic setting with few controllable variables as described by Guba (1981). One factor that is both a strength and a limitation of this thesis is the researchers contextual awareness of the PICUs in Sweden. Guba (1981) believes that it is important that the researcher knows the context that exists where data are collected. The surrounding context must be understood as well as what processes or standards are used in the context. The first author has extensive experience in the PICU context and specific knowledge of being a nurse in the PICU. However, there might be a risk in having knowledge about the context, so the researcher needs to know and clarify what different situations represent. In addition, discussion within the research group representing more of the naive outlook of the context can be seen as ensuring an open attitude to the data. Guba (1981) describes dependability as search for the variation of the uniqueness of the human situation in a study. The dependability in this study is described through the variability in participants and range of experiences sought. The neutrality (Guba, 1981) in the study is facilitated by the researchers attempt to decrease the distance between her and the participants, for example, by the length of the interviews, observations, and establishing the truth value as well as the applicability. Marton et al. (1977) argue that study results can be considered as discoveries. The analysis is done in an exploratory way in which significant statements are interpreted by the researcher (Marton et al., 1977). Marton et al. (1986) believe that the data represents the actual empirical basis for the researcher's

arguments for a particular interpretation. Since the same observations can have different meanings in different contexts, the interpretation must be made in relation to the context. There is no technology that can accurately read back from the data level to the categories that the individual researcher has found. It is a matter of the discovery processes.

6 ETHICAL CONSIDERATIONS

Permission to conduct the study was obtained in two parts. The permission for the first data collection was obtained from the Head of the Clinic, and the Ethical Committee at the Karolinska Institute approved the study on December 5th, 2005. Permission to conduct the second data collection was obtained from the Ethical Committee at the Karolinska Institute 2011/244/31-1. All participants were of legal age and gave their informed consent to participate. They were informed that they could cease participation at any time without giving a reason. Everyone participated after informed consent and research ethical guidelines had been accurately followed. However, there are other ethical considerations connected with interviewing and observations as data collection method. Specifically, in relation to the interviews there were discussions of how the interviews should be performed, when and where the interviews should take place, and whether there was a possibility that the participants would be negatively affected in any way. In order to avoid negative influences, the participants were asked when and where they wanted to be interviewed. All interviews ended with follow-up questions of how the interview and the situation itself had felt and if they felt negatively affected in any way. On the other hand, a researcher who shows interest in someone's personal professional experiences and listens to their personal narrative could also be seen as positive. Ethical considerations in relation to the observations were discussed thoroughly. Were there any possibilities that the nurses, children, or families would feel inhibited in any way? Could there be any situations where the interviewer/observer could be a burden? To avoid this, I informed the nurses who had agreed to be observed that if they felt, or thought that the child or family at any time seemed to be affected negatively with my presence, they could look at me and point to the door. This would be the sign for me to leave, and I would leave without any questions or hesitation. I was dressed as the co-workers in general, sat in a corner and did not participate in any interventions or discussions. I was particularly observant to introduce myself as well as the reason for me being in the room to the parents of the child as soon as the situation allowed. I also informed them that they were free to decline my presence at any time if they felt it becoming intrusive in any way. However, no nurses or parents asked me to leave the room at any time, no matter what happened. In the beginning of the observation, the nurses often looked my way, but this stopped rather quickly and they became used to me being there. Afterwards the nurses told me that they forgot about my presence after a while.

Figure 1: Thesis overview

Domain	Aims	Study design & qualitative methods	Titles of publications/ manuscript
<p>Understanding</p>	<p>To illuminate clinical experiences of pain in the PICU; describing nurses' perceptions of expressions of pain in non-verbal critically ill 2-6 year old children.</p>	<p>A phenomenographic interview study - with horizontal categories (N17).</p>	<p>Uncovering pain in critically ill non-verbal children: Nurses' clinical experiences in the paediatric intensive care unit. <i>Journal of Child Health Care</i>, 15(3), 187-198.</p>
	<p>To explore nurses' perspectives (i.e., their expressed experience, opinions) on clinical judgment of pain in critically ill non-verbal children in the PICU.</p>	<p>A phenomenographic interview study - with hierarchical categories (N17).</p>	<p>Clinical judgment of pain in non-verbal children at the Pediatric Intensive Care Unit - a phenomenographic study. <i>Journal of Palliative Care & Medicine</i>. 1(1) (open access).</p>
	<p>To elucidate patterns in clinical knowledge development and unfold the role of the nurse as facilitator in relation to pain management in the PICU.</p>	<p>Qualitative interview study with content analysis (N30)</p>	<p>A qualitative national study of nurses' clinical knowledge development of pain in pediatric intensive care. <i>Journal of nursing education and Practice</i>. 2(2) (open access).</p>
<p>Cultural interaction</p>	<p>To unfold the meaning of nursing care through nurses' concerns when caring for children in the PICU.</p>	<p>Interpretive phenomenological study with observations and validating interviews (N30).</p>	<p>Caring for children in PICU, an observation study focusing on nurses' concerns. <i>Accepted for publication in Nursing Ethics</i>.</p>
	<p>To elucidate the meaning of caring in the PICU from the parents' perspective.</p>	<p>Interpretive phenomenological study with observations and following interviews (N11).</p>	<p>Meaning of caring in PICU from the perspective of parents. A qualitative study. <i>Manuscript</i>.</p>

7 FINDINGS OF THE FOUR STUDIES

The main findings of the four studies are described below. For a more detailed description of the findings, see the original Papers I-IV.

7.1 UNCOVERING PAIN IN CRITICALLY ILL NON-VERBAL CHILDREN: NURSES' CLINICAL EXPERIENCES IN THE PAEDIATRIC INTENSIVE CARE UNIT (PAPER I)

The findings in Paper I demonstrated how the participating nurses perceive expressions of pain within the PICU context. The findings are divided into three different categories: *pain as a changed, measurable parameter*; *pain as perceived muscle tonus* (with sub-categories *visual* and *through touch*) and *pain as deviating behavior* (with sub-categories *physically observable* and *communicative*).

7.1.1 Changes in the measurable parameters

The data revealed that the nurses in the PICU perceived changes in the measurable parameters as reliable signs of pain expression in the non-verbal critically ill child. These pain expressions included increased blood pressure, decreased oxygen saturation, increased heart rate, and increased breath frequency. A high pulse was experienced as a reliable and direct expression of pain.

7.1.2 Perceived muscular tension

The nurses in the PICU also perceived pain as expressed through the child's body. This category describes the perception of how the child conveys pain by increasing muscular tension. The nurses perceived the character of this tension either visually or by touching the child; therefore, this category has two sub-categories.

Visual perception of muscular tension

A sub-category revealed a focus on the visible signs from the child's body and on any muscular tension. Based on how and where in the body the tension was located, the nurse determined whether it was an expression of pain. Visibly tense and taut body extremities were perceived as a clear sign of pain.

Touch perception of muscular tension

Another way the nurses could perceive muscular tension was by touching the child. The purpose of touching the child was to allow for discrimination of tension caused by pain and tension caused by other things. Children who expressed pain were known to become so tense that they were almost “above” the bed, also described as a feeling of “lightness” when they took the child’s hand in their own hand. The feeling conveyed through the hand contact when the child was understood as not being in pain was described as a more focused and stronger movement. The children became strong and deterrent, not rigid and inflexible.

Altered behavior

The analysis also revealed that the nurses in the PICU perceived pain as contextual, expressed through the child’s altered behavior related to the specific context. The nurses’ perceptions were, to some extent, based on previous experience with children in similar situations, or on that particular child’s previous responses and behavior. The focus in this category was on the alteration from the child’s “normal” behavior in the PICU context related to the informant’s pre-knowledge of children’s behavior, in general, in the specific context. Pain could be perceived as a physically observable alteration, or as a communicative alteration in relation to what the nurse expected of the child in the present situation.

7.1.3 Physically observable alteration

Pain was perceived by observing alterations in the child’s physical appearance from what was perceived as a normal physical reaction for that specific child, or by experience from caring for many children in the PICU. Specific, physically observable, but subtly altered behavior was perceived as a sign of pain, for example, sweating, altered breathing patterns, or constraints in the child’s physical appearance or movement patterns.

7.1.4 Communicative alteration

The child’s behavior was perceived as altered when the limited communication in comparison to what, could be expected as normal.

When *contrasting* the categories it became clear that when nurse’s perceived pain as a measurable parameter, there was a risk of less focus on the whole child as potentially

suffering. When care-giving nurses perceived pain as expressed from the body, via behavior, or through communication, the nurse's focus was on the vulnerable child, and a contextual caring knowledge was developed, with the understanding that children might be able to express their pain through their body or behavior.

7.2 CLINICAL JUDGMENT OF PAIN IN THE NONVERBAL CHILD AT THE PICU – A PHENOMENOGRAPHIC STUDY (PAPER II)

The findings in Paper II revealed how the nurses' clinical judgment is an amalgam of their knowledge skills, practical reasoning, and perceptual acuity that is context based and situational. Three qualitatively different main categories were revealed: (A) *Knowledge orientation*, (B) *Investigating orientation* (with sub-categories *Conflict evasion* and *Participation*), and (C) *Practical orientation* (with sub-categories *Personal experience*, *Confirmation*, and *Communication*) can be understood as three levels of understanding. The most elaborated level, level A, contains judgment orientations represented in all categories (A, B, and C). Level B contains judgment orientations from both categories B and C. The last level C contains only orientations from category C.

7.2.1 (A) Knowledge orientation

The clinical judgment was oriented toward seeking coherence in evidence emanating from the specific child. The nurse related to her own experiential knowledge of children with pain, utilized the parents' specific knowledge of their child's pain cues and mirrored these toward theoretical knowledge on pain, forming a complex judgment process. The focus was on the causality of pain, building on theoretical and experiential knowledge. The context around the child and current events was also considered indicative in the judgment process.

7.2.2 (B) Investigating orientation

The focus was on the specific child's pain and the nurses' experiential knowledge. Collaboration with parents was significant in the way of gaining insight into the child's past history and current developmental status. These nurses perceived the child and the parents as a coherent unit and it was considered vital to ensure that parents understood and participated in the decisions.

7.2.3 (C) Practical orientation

The participants expressed a weak understanding regarding factors and conditions that are considered as specifically contributing to pain *per se*. Characteristics of this orientation included how nurses formulated ideas about the situation that the child is in, relying on comparing the current situation with their experience of similar situations or exemplar cases rather than focusing on the specific child in the specific situation. The nurses' perceptions of how to perform sufficient pain alleviation were validated through the outcome of the chosen intervention. The judgment and the result of an intervention was one single unit.

In this study it became clear that the orientation with the possibility to unfold most variations of the child's expression of pain is the knowledge orientation. This orientation solely supports a holistic approach toward the child.

7.3 CARING FOR CHILDREN IN THE PICU, AN OBSERVATION STUDY FOCUSING ON NURSES' CONCERNS (PAPER III)

A central phenomenon emerging in this study was the complexity in the PICU. Forthcoming was the diversity of urgent demands interplaying and constituting a recurrent demand to highlight and discuss the meaning of nursing care in clinical situations. Throughout the caring acts, nurses' concerns shifted in nuances, but an underlying meaning with various patterns of dominance was seen. A fundamental aspect of caring was shown, namely, the balance of the care given in harmony with the child, from a holistic perspective. When this fails and one pattern of concerns becomes dominant, the nursing care becomes fragmented. The findings highlight a picture of three qualitative variations of concerns disclosed. They are presented as the themes: 1. Medically oriented nursing, 2. Parent oriented nursing care, and 3. "Smooth operating" nursing care orientation. None of the patterns of concerns in nursing care were pure, nor were they mutually exclusive. However, when a critical situation arose, nursing care tended to appear more medically oriented.

7.3.1 Medically oriented nursing

Medically oriented nursing was demonstrated when the focus shifted toward the medical aspect of care. The interventions decided upon by the physician and the

specific medical condition set the frame for the nursing care given. The concern emphasizes the intention of keeping the children's physical needs and condition a priority and maintaining the child's physical appearance. The measurable values became prominent in nursing care. Thereby, the nurses needed to give less attendance to the complexity in the nursing care process, and the parents or families were not involved in the daily care and rarely given responsibilities or chores.

7.3.2 Parent oriented nursing care

The parent oriented care meant that the nurse was oriented toward the parents. Parents were informed about what was going to happen and why nursing was being carried out in a certain way, in an adult language, turned to the child but directed toward the parent and not the child. The child seemed to be viewed as part of the parent, not an individual person with specific caring needs.

7.3.3 Smooth operating nursing care orientation

This variation of nursing care was directed toward the child as a person and a whole human being. The interaction with and integration of the child in the caring situation is of primary concern even when performing other things such as medicine delivery or suctioning. Nursing care and medical interventions were organized in interaction and in harmony with the child's needs, adding value to the nursing care. The meaning of nursing care from this viewpoint is a holistic nursing care, through handling the caring situation with embodied knowledge in a skillful and safe way. Nursing care is esthetically performed, through attentively leading the nursing care, recognizing subtle changes, and following up on minor signs of emotions from the child. Taking on a responsibility to direct the involved persons to see what the child needs. The findings disclosed that the presence of caring from diverse dimensions facilitated the recognition of subtle signs from the child, and made caring individualized as well as attentive to the child's needs.

7.4 MEANING OF CARING IN THE PICU FROM THE PERSPECTIVE OF PARENTS– A QUALITATIVE STUDY

The findings in Paper IV gave an overall impression that from the parents' perspective, caring must be unconditionally experienced and understood as directed toward their exposed child. Parent's innermost urge is that caring must be sensitive to their child's

expressions and needs. The care for the child also aims to build a calm and trustful environment in the eye of the storm for the parents to rest within.

The meaning of caring for critically ill children intends to build bridges through chaos, side by side with the parents to reach the child and to anchor the parents in closeness with the child in the present. It aims to help the child and the parent to feel emotionally close and to build boundaries toward the frightening or crucial situation. The parents' narratives elucidated that they experienced significant aspects of caring in the PICU, prerequisites illustrated in the themes: Being a bridge to the child on the edge, Building a sheltered atmosphere, Meeting the child's needs, and Adapting the environment for family life.

7.4.1 Being a bridge to the child on the edge

After the child was admitted to the PICU, parents experienced a feeling of distance to their child, physically as well as emotionally. The severe condition their child was in frightened and prevented the parents from touching and caring for their child. Through very practical nursing care, like showing how to touch and talk to the severely ill child, the nurse could make it possible for the parent to reach out to the child. This aspect of care demonstrates the importance of anchoring the parents in closeness with their child in the present, helping the child and the parents to feel emotionally close, and building boundaries against the frightening environment. The focus is on helping the parent and child to meet and reconnect in sickness, where needs precede the obvious medical needs, and where the nurse shows the parent how to meet the child's needs.

The findings disclosed that the presence of caring from diverse dimensions facilitated the recognition of subtle signs from the child and made caring individualized as well as attentive to the child's needs.

7.4.2 Building a sheltered atmosphere

Security is a fragile quality for parents in the PICU; thus, an urgent need for parents is to feel secure with the care provided as well as with the nurses and physicians caring for their child. When the nurses showed skills and knowledge beyond the obvious situation the child was in, or when physicians showed knowledge about the child's

history of sickness, trust was built between parents and personnel. When parents were informed continuously and chronologically about their child's treatment, medications, and recovery, the parents felt their worries being eased. When the parents knew what to expect and understood why things were as they were, they felt secure, involved and confident with the care given.

7.4.3 Meeting the child's needs

For parents the needs of the child is of utmost importance. The parents experienced that nurses and physicians had specific engagement in their child, and endeavors to get to know the child better influenced the alleviation of suffering also for the parents. This could be shown simply by doing something out of routine and as expected, for example, providing the child with something that was needed at that time. It was also to prepare the child for upcoming interventions or to redirect interventions when the child became distressed. When doing so, the family also became prepared as to what they might see and their access to their child was not threatened. The mutual emotional availability, openness, and trust that is shown when someone tries to do something personal for the child makes it possible for parents and nurses to work together with interventions around the child.

7.4.4 Adapting the environment for family life

The intensive care environment includes huge challenges for parents. Rooms, beds, and technical utilities result in uncertainty for parents. Invitations were sometimes experienced as an important factor to facilitate closeness to the child. A chair to sit on was experienced as an inviting gesture, sending a signal of being greeted. When caregivers guided the parents to a family space where they were able to be close to the child, this was experienced as an anchoring point.

8 COMPREHENSIVE UNDERSTANDING

The findings in the thesis as a whole suggest the potential for joint caring focusing on the holistic view of the child, including the child as a whole with diverse caring needs. This implies the need for nursing care, which includes qualities that also discern subtle signs of the child's needs. This potential caring skill needs to be highlighted, developed and communicated in order to advance the quality of nursing care and pain alleviation.

Findings in the thesis demonstrate that nursing care fails to be caring for the child when the holistic approach is lacking. For example, as shown in Paper I, if the nurse understands pain as solely being expressed through physiological parameters, other expressions might not be understood and the child will continue to be in pain. In Paper II, some of the nurses judge pain from their own personal views, which might be too narrow to acknowledge another person's ways of experiencing pain. Likewise, as shown in Paper III, the complexity of pain gets lost when not focusing on the child as a person, resulting in a narrow and shallow view of the child. Pain is a complex phenomenon that is aligned with anxiety, contextual factors, workplace culture, the nurses' perceptions of the child's expressions of pain, knowledge about pain, the child him/herself, etc. It is not simply a matter of a pain assessment tool resulting in the nurse giving the child analgesics.

What is evident in this thesis is that the complexity of alleviation of suffering advances when the caring focuses directly on the vulnerable child in the PICU (Papers I-IV). When care is focused on the child or there is active communication with the child, a multidimensional understanding and holistic approach is expressed (Paper I). When knowledge about a specific child is connected with scientific knowledge and contextual factors of importance, a holistic approach is used. This implies knowledge about how the environment might affect the child, what the parents know about their child, and what the child has been through (Paper II). It is most understandable that clinical learning has a practical focus, but in order to reach the embodied knowledge and elucidate subtle signs from the child, the pedagogical questions of what, why, when, etc. must be the driving force. The practical focus needs to become interlinked with a reflective, investigative, and scientific approach – to expand knowledge and learning to become a way of being in the clinical life world. A holistic view of the child is supported by a discussion within the community of practice, which supports integration

between the clinical and scientific knowledge. This, however, is a challenge to implement in the clinical lifeworld. Nevertheless, it is very important that the child be approached from a holistic point of view, at the same time acknowledging different dimensions of needs. Accordingly, the direction of the caring then becomes broadened and reaches beyond the actual clinical situation, adding value to the child's whole situation in the PICU, thereby connecting the child with the now, the family, and the future to come (Papers III and IV).

9 DISCUSSION

This thesis describes nurses' everyday clinical work and knowledge development with children that are at risk of suffering and experiencing pain when cared for within the PICU. The thesis has emerged from a clinical perspective, after being a nurse in the PICU and caring for vulnerable children that are at the mercy of someone to see and meet them and to alleviate their suffering. Questions have been raised, thus, problematizing the impact of nurses' learning and the role of the workplace culture for learning to give adequate care in PICU. The parents' perspective on care in the PICU gave another angle on caring and even more lifted forward the insight that a holistic approach determines if caring is present.

9.1 LIMITATIONS

There are limitations in every study; in this study the researcher had prior experience in the field of PICU. Because of this, it was important to approach the field from a research perspective in order to be able to find anything of significance that were previously taken for granted. One way to ensure this was through observation. Another way was to ask the participants in the interview to describe in their own words. Since the researcher, as stated above, is familiar with the language and culture and has personal experience of the area as a specialist nurse in the PICU, it was important to critically question how this prior experience may have played a role in the analysis of the understanding of language and culture. A disadvantage of the researcher's previous experience of the area may be that it made her more sensitive to nuances, as parts of the stories might be taken for granted. However, Krippendorff (2004) believes that there may be a deficiency and the risk of erroneous conclusions unless the researcher and others involved are very familiar with the environment studied. As the researcher was keen to get answers to some questions, there is a risk of managing the data collection. To manage this balance between openness, control test interviews were carried out in studies I and II, as well as test observations in study III. An interview guide served as support during the interviews in studies I-IV. In this thesis, findings are described in categories/themes that were salient in the different analysis. It is reasonable to assume that nurses belonging in the categories/themes are not static, rather varying over time and in tune with the community of practice in which nurses are engaged. Lave and Wenger (2009) argue that learning is a process of participation in

communities of practice; a learning that gradually increases as the person engages in practice. There might be an aspect of maturity in the nursing and learning process that are seen in some of the categories/themes; however, we are unable to draw that conclusion since none of the studies are longitudinal. Given the relatively small sample of participants and the difficulty in distinguishing discomfort from other forms of pain, it cannot be certain that the participants only described their experience of perceiving, judging, and developing knowledge about pain. However, they were asked to elaborate on their own experience, and the interest lies in their experiences rather than whether they perceive pain in a “correct” or “incorrect” way. Another problem might be that participants can be limited in their ability to verbalize what they are asked for in the interview. In an interview situation, there is always a risk that the descriptions of the nurses might reflect opinions on what they were expected to answer. According to Marton and Booth (1997), this risk decreases if the interview is open and the informant defines the content. We think it is likely that most aspects in the answers reflect the nurses’ and parents’ own subjective thinking; we do not know for sure how care giving in clinical work is conducted when children are believed to be in pain. Our study does not describe how pain might be managed, learnt, or reduced in the PICU. We aimed to understand the nurses’ and parents’ way of thinking, which ultimately offers the possibility of influencing these ways of thinking and, consequently, ways of acting.

Data collection 1 (Papers I and II) was carried out with nurses from only one PICU, reflecting the situation in just this ward, but comparisons with findings from other studies suggest that there are similar conditions elsewhere (Olmstead et al., 2010; Schiavenato et al., 2010).

In data collection 2 (Papers III and IV), we broadened the study field to include all PICUs in Sweden, and a larger number of participants were enclosed in the study as well as parents. We also added observations in relation to validating interviews as a data collection method. This was a way of triangulating the data collection methods and increasing the trustworthiness in the study.

Other methods could have been used, for example, nurses and parents at several hospitals where critically ill children are cared for in adult Intensive Care Units (ICU) could have been interviewed as well, but this might have provided less in-depth information.

In the analysis of our data, we strived to unfold the latent meaning as well as the manifest meaning. The manifest meaning can be seen in descriptions of actual behaviors and organizational structures. The latent meaning answers the underlying choice of guidance and meaning of learning relations in clinical knowledge development (Schiavenato & Craig, 2010). In data collection 2 (Papers III and IV), all PICUs in Sweden were included, and it can be argued that the findings of the studies are not influenced by the culture at a single PICU as it might be in data collection 1 (Papers I and II).

9.2 GENERAL DISCUSSION

Critically ill children are vulnerable and in need of others to recognize their needs, which exposes them to the risk of suffering from untreated pain (Ramelet et al., 2004). Johansson and Kokinsky (2009) came to the conclusion that pain in the non-verbal critically ill child is not easy to differentiate from discomfort of other origin, especially when it comes to anxiety. Even if reliable and validated pain assessment tools are of importance, they can never replace the perception of subtle pain expressions from the individual child. According to Benner (1982, 1984), to perceive subtle expressions of pain requires attention and tactile skills, developed through clinical “connoisseurship.” This is shown only in Paper I, where it becomes evident when nurses focus on the “patient oriented” perspective. When doing so, nurses express that subtle signs of pain are revealed. Benner (2002) emphasizes the need for the nurse to “meet” and come to know the patient in order to respect his or her concerns and identity. This is a very important finding, considering Van Hulle Vincent et al. (2010) argument that there is a relation between nurses’ cognitive representation of pain and their choice of pain alleviation. If the nurses do not focus on the child and understand the child’s subtle signs of pain, some nurses might not find it necessary to look for other expressions of pain or alleviate pain. It is important to remember that research shows that change in measurable parameters is not a valid sign of pain in the PICU (van Dijk et al., 2005). Furthermore, as shown in Paper II, nurses attend to the child’s pain from different understandings and preparedness to use their experiential as well as theoretical knowledge in the clinical judgment process. Most of the nurses in this study claimed to have embraced the contents of assessment tools into their knowledge and accordingly did not have one at hand when judging pain. Allowing their clinical judgment of pain to

vary from the perspective of discovering the child's pain reveals how they think and use their knowledge in practice (Benner, 1984). However, findings show how some of the nurses focused on the situation itself rather than the child in the situation. Benner (1982, 1984) and Benner et al., (2009) stress that the nurse's judgment process will vary according to her knowledge; moreover, Benner et al. (2009, p. 200) assert that clinical judgment refers to the ways "in which nurses come to understand the problem, issues, or concerns of patients, to attend to salient information, and to respond in concerned and involved ways." The findings in Paper II reveal that it was only within category (A) that nurse's knowledge about children's pain behavior seems to be consciously applied and related to the specific child. The clinical judgment process is clearly conscious and connected to the intended outcome, namely, alleviation of the child's pain. Since the child's alleviation of pain is dependent on the outcome of the judgment process, it is of importance to reflect on, unfold, and discuss the implications that the knowledge orientation underpinning the process has for pain alleviation.

When looking at the meaning of nursing care in the PICU, the second data collection started. This data collection was broader and contained all of the PICUs in Sweden. The presence of medical concerns is understandable in a PICU context where children are admitted due to critical conditions. However, the child as being of primary concern and the awareness of other caring needs than the physical ones was sometimes found as painfully not visible (Paper III). The meaning of care within a medical oriented nursing does not offer anything extra for the child as a whole human being. Arman and Rehnsfeldt (2007) highlight that encounters with patients can increase the suffering when not acknowledging the patient as a whole human being and neglecting the patients' needs. Children are even more vulnerable in this aspect. When situations become more medically demanding or critical, nurses tend to become even more medically oriented, thus, strengthening the objectifying view of the child and jeopardizing the child's well-being in the situation. There is a deep ethical concern that not being open to the child's needs and well-being throughout the nursing care, but rather treating the child as objects causes a secondary suffering, caused by healthcare. This points to an ethical complexity to deliver good nursing care in a way that continues to focus on the child's needs as first priority. It is most important for children to be seen and listened to as individuals. (Brady, 2009; Forsner et al., 2005; van Staa et al., 2011). Only when nursing care was performed as "smooth operating" nursing care were the children seen as whole human beings and the meaning of nursing care was

seen as holistic. Research by Arman and Rehnsfeldt (2007) has shown that the caregiver's ability to act as a fellow human being adds value for the patient through the nursing care as well as adds comfort in the situation. The caregivers readiness to see, meet, and share the patient's struggle with suffering is an essential part of nursing care. Benner (1994) argues that nurses engaged in caring must be able to take on the patient's perspective in order to meet the patient's needs. This was clinically evident in this study as the nurses acknowledged subtle changes in the child's appearance, physically as well as emotionally, and attentively incorporated them into the art of nursing care. When elucidating the meaning of caring in the PICU from the perspective of parents, it emerged as central, holistic, and individualized in an adaptive environment. Moreover, it became even more evident that the meaning of caring is holistic and that parents and nurses can meet and strive for the same direction, the good of the child, when children are seen as whole human beings. Parents' perspectives of the meaning of caring is explained as the importance of providing expert physical care combined with fulfilling emotional needs and supporting continuing daily parental care for the child in an inviting environment. Parental involvement with the sick child can be supported by an open and giving relationship between parents and healthcare workers.

It is obvious throughout this thesis that the meaning of care and knowledge development is influenced by culturally based tradition. This tradition sometimes seems to influence nurses to neglect the child's caring needs, letting the culturally based traditions steer what is important to recognize and attend to within the context of the PICU. From an organizational point of view, a narrow objectifying care must be seen as a disrespectful and violent act toward the child. On the other hand, there are nurses who add something more and offer a holistic perspective, when perceiving expressions of pain, judging pain, and in the nursing care situation. These nurses extend beyond traditions, rules and routines to add the little extra, which gives the patient a notion of being a whole person, a fellow dignified human being, seen and listened to. Such skills should be the PICUs leading star for learning development to enhance the continuous development of the quality of care. Sufficient alleviation of pain and suffering should then naturally follow.

10 CONCLUSION

This thesis has shown that pain alleviation in the PICU is a complex task within the practice, which is interrelated to the PICU culture and is not only influenced by the nurses' perception, experience, and knowledge of the child's expressions of pain. When the child is seen as a whole human being with specific needs, the nurse's possibility to become aware of the child's needs and add value to the care given increases and as such alleviates the child's pain. There is also a lack of a facilitating structure for learning within the clinical practice, which is a lasting problem when it comes to alleviating the vulnerable child's pain. Therefore, the organization needs to facilitate the nurses' individual learning to view the child in a holistic way and embrace scholarly learning about children's pain. To improve the cultural influence of what can be seen as good nursing care within the PICU, the concerns in the nursing care situation, which have been shown to be the watershed of the meaning of nursing care, needs to become elucidated. According to Benner and Wrubel (1989), the engagement with the patient is the key to improved quality of nursing care. Perceiving expressions of pain in non-verbal critically ill children in the PICU is no exception. It is of even more importance to children's well being in this particular context that the health care organization systematically facilitates the development and transition of knowledge regarding pain-related expressions as well as experience based knowledge of pain. Furthermore, the PICU organization has an obligation to support and promote the implementation of pain assessment from diverse perspectives for all children, no category excluded.

11 CLINICAL IMPLICATIONS

To increase the possibility of pain alleviation and quality in the clinical setting, it is of importance to attend to the caring culture and build a safe collaborative culture that is patient centered. This requires an environment that allows for open discussion, where questioning and reflecting is a natural part of the culture within the group. Discussions and questioning should be based on the clinical context and the co-workers' different experiences of what happens when the child feels pain. Most important is that the meaning of care in the PICU be directed toward a holistic view of the child. To individualize the nursing care given and strengthen the holistic view in the nursing situation, we suggest that two nurses participate in nursing care during critical interventions such as intubation, etc. One of the nurses can attend to the child's medical and physical needs, whilst the other attends to the child's needs as a whole human being, sharing the child's vulnerability and suffering in the situation as well as supporting the well-being (Arman & Rehnsfeldt, 2007; Benner, 2003). Strengthening the status of nursing care through nursing care rounds can achieve this. Thus, all of the child's caring needs, in accordance with the caring process suggested by Benner (2003) and Benner and Wrubel (1989), are highlighted in the same manner as the child's medical needs are attended to through the medical round. Furthermore, a nursing care plan for each individual child needs to be paid attention to on an everyday basis. It is also suggested that two nurses become involved in caring for the child in critical situations to ensure that the needs of the child beyond medical treatment are secured.

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