Nurses' Interactions with Families and Children During Pain Management

By

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Abstract

Title: Nurses' Interactions with Families and Children During Pain Management

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This study explored the ways in which nurses interact with families in treating children's pain. There has been little systematic study of those interactions, even though nurses work with families regularly. The descriptive study was a secondary analysis of data from a study conducted by Gedaly-Duff and Holland (1994), which asked nurses to describe their experiences in learning to treat children's pain. One theme that emerged was the role of the family. This study looked at the data on the family and explored the different ways in which the family was viewed by nurses.

The data were collected from 9 acute care nurses. There were eight females and one male. Their education was baccalaureate except for one associate nurse and one diploma nurse. Three focus groups, each consisting of two to six nurses, were interviewed one to three times. Verbatim transcripts of the audiotapes were analyzed using grounded theory strategies of open coding, constant comparative analysis, and memo writing. Limitations of the study were that the research questions were not directly asked of the participants. There were only nine participants in the sample, so theme saturation was not reached.

The study found that during the process of caring for children's pain, nurses involved families in fluid, complex ways. The nurses believed that families knew their children best, nurses needed to gain parental trust, and they understood the family as a unit and as individuals simultaneously. Nurses interacted with families in four different ways: a) nurses and families collaborated to manage pain; b) nurses guided pain management using three different family perspectives: the individual as focus, the family as focus and the family as the unit of care (Wright & Leahey, 1994); c) nurses perceived families as guiding pain management; and d) nurses and families had opposing views of pain management.

These findings suggest that novice nurses can be taught how expert nurses engage families. Expert nurses can also show insurance companies what nurses do to influence outcomes and lower costs. Further research needs to be done on other sets of data (Gedaly-Duff et al, 1996a, 1996b) to confirm and expand the categories of nurses' interactions with families and children during pain treatment.

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Chapter I

Introduction

The health care of children is generally provided by their families (Hanson & Boyd, 1996). The health care of children involves treating their pain. In 1991, 170 children per 1,000 had surgery; sports injuries occurred to 1,062 per 10,000 children, and 225,000 children were injured in motor vehicle accidents (Schmittroth, 1993). When children need the expertise of health care professionals to treat pain, families want to play an active part in the care of their children. Families want to be viewed as competent by health care professionals. Parents feel that they know their children and are the best source of information about their children's responses to pain, including symptom behavior (Robinson & Thorne, 1984). Expert nurses appear to recognize family expertise and work to establish and maintain the family's role in delivering care (Chesla, 1996). Yet little has been written about the ways in which the expert nurse goes about involving families in the care of their children.

The observations, actions and clinical decision making that are involved in the expert nurses' inclusion of family have not been described in research. However, anecdotal descriptions of nurses working with families are available. For example, McGrath (1990) cited the case of a 2-year-old child who had recently been diagnosed with diabetes. His behavior grew out of control when invasive procedures became necessary. Health professionals saw the mother as being unable to help her child because of her distress over the responsibility for total care of the child and the need to do

injections. Using a teddy bear to demonstrate the procedure, the child and his parents were taught ways to cope with the pain of injections. The parents were taught to comfort the bear and to explain to the bear what was going on. Only then did the child and his parents overcome his fear of the necessary procedures. The case study report did not indicate whether the parents were asked what might help their child and family; emphasis was on teaching parents how to help their child cope with painful injections.

The study reported here explored the ways in which nurses interact with families and children during pain treatment. The study built on the analyses of Gedaly-Duff and Holland (1994), Gedaly-Duff, Holland, Bentson-Royal, Madden, Nguyen, and Wright (1996a), and Gedaly-Duff, Sabin, Nava, and Hill (1996b). Those three studies examined expert nurses' experiences in caring for children with pain. All found that nurses involved families in pain treatment of children. The studies, however, did not analyze the descriptions of nurses' actions related to family involvement. The current study therefore focused on nurses' perceptions of how they interacted with families and children during pain treatment. Using secondary analysis, the data were analyzed to explore ways that nurses' involved families in the care of children's pain.

Statement of the Problem

In clinical observations of hospital nurses, the investigator has seen conscious interactions between families and nurses in the management of children's pain. Yet nurses' and families' interactions during pain management have not been well documented. There is little written about the ways in which nurses gather knowledge of pain cues and integrate this knowledge with their knowledge of family. Exploring how

nurses interact with families during the care of children will provide a descriptive base for learning more about the role of families in their children's pain management. Nurses can then better integrate families into care.

Significance to Nursing

Nurses manage the pain of children, and their abilities to use objective and subjective pain cues have developed through experience (Benner, 1982). In the past, educational programs did not teach nurses strategies for treating children's pain (Gedaly-Duff & Holland, 1994). Describing expert nurses' interactions with families will help to explicate this, so that nurses may then be taught ways of working with families whose children have pain.

Chapter II

Conceptual Background

This section examines how nursing science has viewed families and examines the pain literature from a family perspective as background for understanding families and the nursing care of children's pain. Three theories of nursing of families are presented and their similarities and differences discussed.

Friedemann's Family Nursing Approach

Friedemann (1989) discussed three levels of family nursing: individually focused family nursing, interpersonal family nursing, and family systems nursing. In individually focused family nursing, nurses develop a relationship with each individual in the family. The individual is viewed as the client and is seen as a subsystem of the family. Nursing goals are oriented to the physical health and personal well-being of individual family members. Interpersonal and system change may occur as byproducts of interactions.

At the second level, interpersonal family nursing, the nurse looks at family processes among family members, such as defining family roles, decision making and limit setting. The goals are to facilitate understanding within families and to support family members. Nurses may intervene when there is conflict or misunderstanding between family members. System change, as described below, may be a byproduct of interpersonal family nursing.

At the third level, family system nursing, the nurse plans for system changes that promote increased harmony among family members and their surroundings. Family system nursing sees interpersonal and personal changes as part of a master system plan.

Nurses assess the need for system change based on a holistic understanding of families. Nurses at this level understand the complex interactions of a multitude of family factors. They know that the family is more than the sum of its parts. Interventions are directed both toward individuals and toward the family interactional system in order to change the system. Nurses may see a need to care for a patient at home by examining the family system's internal resources and their willingness to accept external assistance. Nurses may then formulate strategies with families that encompass individual and interpersonal actions and lead to a system change within the family. Nursing at a family systems level may involve three levels: individual, interpersonal and systems, as necessary. Nurses who practice at this level have developed their care from the other two levels, building on each to attain the third level.

Hanson's and Boyd's Family Nursing Approach

Hanson and Boyd (1996) discussed four approaches to family nursing: family as the context for individual development; family as the client; family as a system; and family as a component of society. Nurses who view the family as context for individual development focus on the individual. The family serves as a resource or stressor to the individual. Nurses explore how families affect individuals.

The nurse who views the family as client, assesses each member of the family and provides care to all of them on an individual basis. Interactions between family members, not the family system, are considered.

The nurse who sees the family as a system views the interactions between family members and subsystems as important. The interactions of the parental dyad and the child or a sibling dyad are targets for nursing interventions. The family is considered a unit.

When the family is considered as a component of society, the family is viewed as an institution in society which interacts with other institutions. The family communicates with other societal components such as school, church, health care, social groups and financial institutions.

Wright and Leahey's Approach to Nursing of Families

A third family nursing theory is that of Wright and Leahey (1990). They discuss four ways of viewing families: the individual as focus; the family as focus; the family as a unit of care; and the family as a system embedded within other systems. Their approach is similar to Hanson and Boyd's but adds complexity at the fourth level.

When the individual is the focus, nurses focus on children and involve families only as needed to deliver care to the child. For example, when a child is in pain, the family may be asked how the child has reacted to pain in the past. Family involvement in assessment and treatment of the child in pain occurs only when necessary to treat the child.

When the family is the focus, nurses look at families and their reactions to specific situations, and see individual as background. This approach is illustrated by the assumption that families shape their children's expressions of pain. Families in the case might be asked about their perceptions of their children's pain and how they are dealing with it. A child's pain would be treated from the family viewpoint rather than the child's.

In viewing the family as the unit of care, nurses see the whole system as integral to pain care. The interactions among all family members are the bases for developing a plan of care for the child. The family may include subsystems, such as mother-child, mother-father, father-child, and child-sibling, or the whole family system. It is important to assess the family system to understand and plan care.

When the family system is seen as embedded within systems, the family interacts with other systems from the cellular level to large systems in society. Using this model, nurses work in the system where the greatest change may occur. When children are in contact with the health care system in the hospital, nurses help the family interact with the hospital and the various subsystems within the hospital. At the same time, nurses may assess the physical status of the child, and keep an eye on fluid and electrolytes. For example, this investigator has observed nurses caring for critically ill children, assessing minor changes in status and reacting to them, while at the same time, assessing the family and how the family functions as a family and as individuals. Nurses work with, and for, the family to ease interactions with other systems such as medicine and social work.

Comparison of the Friedemann, Hanson and Boyd, and Wright and Leahey Theories

The three theories presented here represent views of how nurses care for families and the individual. Friedemann's approach (1989) explains how nurses learn more complex ways of dealing with families as they cope with their children's pain. Nurses start at the beginning level and build upon their learning to develop complex ways of intervening with families. The theoretical models of Wright and Leahey (1990) and Hanson and Boyd (1996) differentiate the focuses of nurses but are not hierarchical like

Friedemann's theory. Sometimes, one view is used more than another, depending on the type of intervention needed for the family.

The works of Wright and Leahey (1990) and Hanson and Boyd (1996) are virtually identical in the first three areas of each model, but they differ in the fourth. Hanson and Boyd view the family as a system that interacts with other systems, such as church, school, and health care; nurses are part of a subsystem of health care. Wright and Leahey have a different point of view. They see nurses working on a multitude of levels from the microcellular level in the patient to the macro level of the family reacting with other systems such as school, hospital or spiritual systems. The nurse works at the level where the most effect can occur.

Each model gives a theoretical view of nursing and the family. The literature reviewed below is based on Wright and Leahey's theory (1990) because this theory explicitly includes the concept of the family system embedded within other systems. Pain is an unpleasant sensory and emotional experience associated with actual and/or potential tissue damage and is also felt at other levels by children and their families. Wright and Leahey's theory also takes this into account.

Chapter III

Review of the Literature Pertaining to Families and Children in Pain

Wright and Leahey's (1990) family nursing theory has four approaches a) the individual as focus, b) the family as focus, c) the family as a unit of care, and d) the family system as a system embedded within systems. The literature is reviewed here in four sections reflecting these approaches on levels of care. The review of the literature concludes with a review of findings from the studies of Gedaly-Duff et al (1994, 1996a, 1996b) using the Wright and Leahey theory.

Families are highly involved in the pain experience. Flor, Turk and Rudy's (1987) comprehensive review of chronic pain and families concluded that children learned health care attitudes and behaviors and pain reactions from their families. Families are where health problems are first identified and responses to illness occur. Doherty and McCubbins (1985) also said that the family system is an important component in the care of children's health. Families play an active role in illness and pain. Learning how families deal with pain provides practitioners with a basis for understanding the dynamics and contributions made by families during painful episodes. For example, Maron and Bush (1991) have discussed two ways in which families may influence children's reactions to pain. Some families feel that children should be stoic and should show little visible distress. In contrast, other families believe that their children should be demonstrative, and give dramatic expression to their pain.

While the nature of the interaction of nurses and families has been theorized to some extent in the literature, how nurses engage families in pain treatment has not been well described. In their meta-analysis of 27 studies on pain management, Broome, Lillis and Smith (1989) found that 60% of the time, an adult was present during pain interventions. They speculated that there may be a relationship between the parents' presence and pain outcome. There was no discussion, however, of the ways in which nurses and families interacted when families were present.

It has been suggested that the importance of families has been underestimated (Flor, Turk, and Rudy, 1987). Families were where children learned behaviors and responses to pain. Pain researchers have recognized the influence of family but few investigators have described how it applied in actual practice.

Individual as Focus

When nurses focus on children and pain, they are seeing children in the context of family. Families are in the background. They are only involved when needed to treat their children's pain. Child-family interactions are viewed as helping children but children are not viewed as affecting their families. Most pain studies have focused on the individual, on the child. They looked at the family as an instrument for pain management, a roadblock to pain treatment, or as the context in which reactions to pain were learned.

Some studies have viewed families as an instrument for pain treatment and as an useful but not essential in pain management. Weekes, Kagan, James and Seboni (1993) used parents as instruments for pain relief. Their sample included 20 patients aged 11 to 19 from pediatric oncology and renal outpatient clinics. They found that parents holding

their adolescent's hand decreased procedural pain. The study indicated that children wanted their parents with them during painful procedures. Parents were viewed as being able to help their children adjust and were desired by the child as a support person. Handholding was also effective if the nurse was the support person, making the nurse a surrogate family member. Families, however, were perceived as an instrument for pain treatment rather than as a dynamic part of the process.

In a study by Gaukroger (1993), parents helped their children use patient controlled analgesia (PCA) to insure that PCAs were used appropriately. One thousand children and their parents at Adelaide Children's Hospital were given instructions on the use of PCA. Parents reinforced the teaching and helped their children recognize when a pain medication was needed. The parents also identified when their children were in too much pain and prepared their children for painful procedures. Thus, parents were viewed as a way to provide pain relief. Parents' perspectives and fears, however, were not addressed.

Families' anxieties, fears and beliefs can be roadblocks to pain management. Broome and Endsley (1989), for example, found that mothers' behaviors affected their children's reactions to pain. The researchers observed 83 preschool children and their mothers during immunization. Prior to the injections, mothers were asked to rate theirs and their children's anxiety; ratings of anxiety and distress for both mothers and children were recorded. Twenty-five of 40 mothers who emphasized the situation, either by saying that it would hurt a lot or there would be no pain, had children who were very distressed or slightly distressed. The children of mothers who showed neutral emotion or only

slightly emphasized the situation showed minimal distress. Thus, Broome and Endsley found that sometimes parents were reassuring, while at other times they increased their children's anxiety. They did not, however, examine how children affected mothers or other family members. More needs to be learned about nurses' treatment of mothers' anxiety related to their children's pain.

Gedaly-Duff and Ziebarth (1993) found that mothers feared narcotic addiction during their home treatment of their children's post operative pain . The focus of the study was on how mothers managed their children's postoperative pain at home. Seven mothers were interviewed in depth two to three times. All the mothers identified fear of addiction as a reason to undermedicate. One mother described her child wanting more codeine soon after the last dose; the mother interpreted this as an addictive behavior instead of a sign of inadequate pain control.

Nolan (1993), in a discussion of family beliefs and fears, noted that improved communication between nurses and parents usually improved children's pain management. Nolan pointed out that some families view the "stoical endurance of pain" as a way to build character and they may reject all pain interventions. Nolan concluded that most parents would, however, allow management of the child's pain if they received proper education. Nolan, nevertheless, identified the problem of challenging parental wishes when those wishes conflict with recommended pain management.

In a study by Naber, Halstead, Broome and Rehwaldt (1995), 17 children and parents were videotaped during 44 painful procedures. Through analysis of videotapes, the authors described parental behaviors that helped or hindered children during the

procedures. The study saw the family as needing to be taught to interact with their children during painful procedures so children will deal better with the painful situation.

Family As Focus

When the family is the focus, research examines how the family is affected by the individual and explores the effect of the child's experience on the family members. Family members' feelings and reactions to the pain are investigated since children's pain affects the function of the family.

One study described family factors that influenced children's cancer pain management (Ferrell, Rhiner, Shapiro & Dierkes, 1994). The study included both the family as focus and the family as unit of care. Thirty-one parents who had children in the hospital receiving medication for cancer pain were interviewed, using open-ended questions. The parents were asked about the experience of cancer, cancer pain, the perceived role of family members, the impact on the family, and advice they would give to health care providers and to other families. The child's pain lead to marital strain, sleep deprivation, loss of a normal life, parental failure and guilt, and disruption of the family system. This study documented that families are directly affected by children's pain experience. Parents reported feeling their children's pain and a sense of helplessness and of being unprepared to deal with the pain.

Families felt that health professionals needed insight beyond the developmental and physiologic aspects of pain care. They needed to understand how families influenced pain. Families described how they were unprepared to deal with the cancer pain. While this study did not address the nurse and family as partners in pain care, it did view the family as needing to be considered in pain care.

Family as Unit of Care

The view of the family as unit of care sees the family as a whole, examining the interactions among family members to establish a plan of pain care. Pain can disrupt the family system and its subsystems, including dyads such as the mother-child and triads such as child-sibling-parent.

In a qualitative study of the impact of pediatric cancer pain on the family, 31 families were asked what doctors/nurses could do to relieve pain (Ferrell et al., 1994) . Families wanted health professionals to listen to the families and children. Families wanted recognition of their knowledge and expertise about their children. Families knew they had the pain history of the children, which health care professionals did not have. Families wanted to be partners in pain management. One parent said, "they (the parents) know a little bit about the child, and if the doctors and nurses would just listen to them a bit, it might make their decisions on what they have to do for the child a little bit easier. " (p.384). Families had special pain knowledge of their children: "You can tell by his face. Some people thought he was smiling because you could see his teeth, but that's his pain face" (quote from a parent, p.373). Children expressed their pain in various ways, and parents were able to interpret their children's expressions. Families were thus

able to inform nurses and doctors what the behaviors meant. The families knew their children and their normal behavior and helped nurses learn children's pain cues.

Similarly, Melamed and Bush (1985) found that when children were hospitalized, parents wanted to be viewed as competent to care for their children. Families wanted to retain their place as caregiver, and felt a loss of control when their child was hospitalized. They felt a loss of the role of primary care giver to the hospital staff because of the unknown nature of the hospital and/or the disease. Melamed and Bush suggested that parents are usually the ones who know their children best. Parents know their children well enough that they are able to discern pain behavior through nonverbal cues that nurses would not know. They know the children's previous reactions to pain and what their children look like when comfort is attained. The connections between family members are evident. Families want to maintain the family dyads during hospitalization, they want to use their knowledge and expertise to continue to care for their children while in the hospital.

Families have been forced to seek out specialized pain services when no one else took the child's pain seriously (Ferrell et al., 1994). These families wanted to see their children as comfortable as possible and to be listened to by primary care providers. Families were active advocates for their children. When they were not heard, they sought out others who listened and could help their children achieve pain control. Families looked for pain relief for their children, which helped the family comfort level.

The family as a unit of care has not been widely examined in the literature, even though pain affects the whole family. Families live with the child who is in pain. Families want to be viewed as competent, they want to be listened to and to have their children listened to as well (Ferrell, Rhiner, Shapiro & Dierkes, 1994).

Decreasing family stress was the focus of a study of children with congenital heart disease who were undergoing cardiac catheterization (Campbell, Clark, & Kirkpatrick, 1986). Twenty-six children and their parents were waiting for elective cardiac catheterization. The 14 children in the control group were given a brochure that discussed cardiac catheterization and hospitalization. Families and children in the experimental group took part in three sessions. In the first session, the parent and child met separately with a staff member. Their concerns about medical issues were discussed and skills training and homework were given. In the second session, children learned stress management techniques with a therapist while their parents watched. During the third session parents and children rehearsed the new skills in an imaginary setting. When the children were admitted for the catheterization procedure, they assessed their own fear level. Trained staff members recorded behavior at three stress points: venipuncture, administration of pre-catheterization medication, and separation from parents. One week later, the control group and experimental group of children and parents were asked to assess the hospital experience. Less stress was felt by the families and children in the experimental group. The study affirmed the importance of the parent-child relationship, seeing the family as a unit. The study findings emphasized "the parent assuming an active

role as therapeutic ally, rather than the more passive role as recipient of information only."

One study looked at families' perceptions of what makes a positive working relationship with health care providers (Knafl, Breitmayer, Gallo, & Zoeller, 1992). Fifty-one sets of parents of children with chronic illness were interviewed to find out what behaviors of health care providers promoted and sustained a positive working relationship with families. Only families in which both mother and father participated were included. The interview questions focused on contacts with the health care system in the last year concerning the child with a chronic illness; past contacts that stuck out in the parents' minds; and advice the families would give to doctors and nurses.

Parents commented on both positive and negative relationships. When parents were dissatisfied, they felt that communication was poor and their efforts were not valued. Families were dissatisfied when health professionals were unable to relate to the children. Families reported satisfactory relationships when expectations were exceeded, particularly in terms of interactions with the parent and the affected child. The parents felt that it was important that the provider related to the child and valued the child's input, seeing the child as a part of the team. In these instances, parents felt they had a positive working relationship with the provider and the provider had confidence in the parent.

Parents suggested a number of ways to help create a positive health care experience for the family as a unit. Families' recommendations included: a) a need for information exchange, b) the importance of an interactional style, c) the establishment of a relationship with the child, and d) recognition of parental competence. Families valued

the communication skills and the collaborative spirit of providers. While this study did not address pain specifically, it did focus on family as a unit in discussing the health care experience in general.

In summary, families as units have certain expectations of nurses. They want to be viewed as the expert on their child. They want to have good communication with the nurse and they expect that communication will include their children. Families need to feel valued.

Systems Embedded Within Systems

The perspective of the family as a system embedded within systems views the child, family, and illness as interconnected. Nurses work with systems to find the point in the various systems where the greatest change can occur (Wright & Leahey, 1990). Nurses can manage pain in a variety of systems-- the hospital system or the family system. If the family needs help interacting with the physician, the nurse can facilitate this for the family. If the family is in need of social services, the nurse can help them connect with the appropriate person. The nurse also analyzes the patient and the illness and intervenes as necessary at the level at which the greatest effect will occur.

> While there are no articles describing the family as a system within other systems in regard to pain management, this can be illustrated by the following clinical example: Parents found their child on the couch unresponsive. The child was brought in by paramedics, intubated and stabilized hemodynamically. When I assumed his care, he was ventilator dependent and on a variety of drips to maintain his existence. But nothing was going to bring him back. His parents were

not, as yet, believing the prognosis. I was attentive to the child's physical needs: adjusting the IVs, maintaining the ventilator, turning and positioning as needed. It was important to provide him with as much comfort as possible. But I was also very much aware of the family and their emotional pain. Pain that may have been felt by the patient was addressed by positioning and a morphine drip.

The main system that needed intervention was the family and its emotional pain. The family's most pressing need was to find a way to transition from being loving parents to a family in mourning. As I cared for the boy, I discussed the situation and found ways for the parents and the extended family of grandparents, aunts, uncles and a sister to start the process of mourning. They wanted to know the correct thing to do. So it was discussed what would be right for them, not what was right for others. No one rushed the family to make the decision to extubate. The family went home and brought back the child's favorite things. He was dressed and the room was set up for the family to say good bye in a way that was meaningful for them. The staff then left the room and let the family say their last goodbyes before all signs of life were gone. When the family was ready, the child was extubated. The emphasis of the pain care was on the family system because the need was the greatest. Their emotional pain was the area that needed the strongest intervention.

This situation illustrates the family system embedded within systems perspective. Taking this perspective, the nurse met the physical needs of the child, intervened with the health care setting, and intervened with the family to bring about change within the family system. Thus, nurses in practice recognize and treat pain at a variety of levels; however, their practice is not well documented in the research literature.

Findings From the Work of Gedaly-Duff and Colleagues

Three interconnected studies by Gedaly-Duff and colleagues have examined expert nurses' experiences in caring for children's pain (1994, 1996a, 1996b). Thirty-eight nurses were interviewed in small groups and asked to discuss how they learned to treat children's pain. Qualitative analysis was used to examine the data. All three studies contained frequent mentions of the family. Nurses volunteered information on families as they described their experiences in treating pain. Thus, families were part of nurses' stories about children's pain. These expert nurses assessed families' level of knowledge about pain, family involvement and empathy with the child to shape nursing actions (Gedaly-Duff et al., 1994, 1996a, 1996b).

In the first study (Gedaly-Duff & Holland, 1994) 11 critical care nurses were interviewed in three groups in order to learn from expert nurses how they treated pain in children in critical care situations. Nurses described their interactions with families about pain. For example, they listened to parents to help them assess pain. One nurse told the following story of a ten day old infant who had cardiac surgery:

> [Shift change] Report given to nurse was that the "baby had been real fussy and just having a hard time" And so went in and found the mom's upset you know. `I just feel there's something wrong and I don't know what's wrong.' Nurse then discovered that the baby was cold and had not had pain medicine at regular intervals throughout the day. She warmed the baby and medicated. "And mom settled down and everything went better. She [mother] wasn't nervous she kind of relaxed, and then she talked, she even verbalized `She looks peaceful now'. She's sleeping now. She hasn't been sleeping for most of the day--she's just been crying." (pg. 20)

This nurse was sensitive to the mother/child dyad, and she listened to the mother's concerns and anxiety. The nurse also assessed the infant and instituted interventions to decrease the mother's anxiety and comfort the infant. This is an example of nursing care directed toward the family as a unit.

Gedaly-Duff and Holland (1994) wrote that even though the nurses that they interviewed knew the patterns and course of the illness related to pain, they turned to families for knowledge of their children. Nurses valued observing the interactions between parents and children, and parents' statements concerning their children's pain.

In a second study, Gedaly-Duff, Holland, Bentson-Royal, Nguyen-Le and Wright (1996a) examined acute care nurses' experiences. Nine nurses were interviewed in four small groups. A major theme that emerged was trust, including development of trust, between nurses and families. One nurse said:

> So sometimes it's just building up that trust with the families to know that you really are going to stay on top of it and to help them learn cues that they need to know so that when they go home, they can tell they need to intervene or when not to. (pg. 11)

Thus families were viewed as needing to learn new ways of caring for their child. A bond developed between the families and nurses that allowed information and strategies to be shared. Families were the focus of nursing care in this example.

In Study Three, Gedaly-Duff, Sabin, Nava, and Hill (1996b) interviewed 18 nurses from pediatric and neonatal intensive and acute care units in four groups. Again, the theme of family was frequently mentioned in the accounts of pain treatment. Both the emotional and physical pain of the children and their families was addressed. Families were mentioned as a way that children learned how to react to pain and as a source of information about each child's individuality. One nurse said:

> I usually really trust what moms say. And I think they know how their babies sleep and I think that can be exhibiting pain and I usually will medicate the child. . . . A lot of times I will involve the mom in that decision, "do you think I should wake her to medicate?"(pg. 5)

This story illustrated the nurse's involvement of the mother and her validation of the mother's knowledge of her child. The child was the focus of nursing care with the mother supplying information to help the child.

In all three set studies, the theme of family was present. In most of the stories told by the nurses, the family had a prominent role in pain treatment. The family was a source

of knowledge, and validated nursing assessments; and when a neonate was in pain, the family was part of a joint effort to learn about the patient.

In the third study, nurses described three ways of working with families. First, the nurse assessed the family for empathy for the child in the experience of pain. Then, if the family had empathy for the total situation, the nurse used the family to assess and manage the child's pain. If the family was not judged empathetic to the child, the nurse planned interventions to promote empathy with the child's pain experience. If the family was not available to the child for pain care, the nurse planned interventions to promote involvement of the family and, at times, would act as a surrogate family for the child. Finally, expert nurses identified emotional pain of the family as a type of pain that needed intervention and as an area which nurses were adept at handling (Gedaly-Duff, Sabin, Nava, & Hill, 1996).

Nurses built relationships with both children and parents. They sought parents' knowledge about the unique needs of their children and believed that parents expected to feel genuine concern by the nurses for their children, especially for their pain care needs. The parent and nurse used each other to learn about the child's pain cues (Gedaly-Duff, Holland, Benston-Royal, Madden, Nguyen-Le, & Wright, 1995).

Need for Further Study and Gaps in the Literature

Pain that requires health care intervention is a new experience to families. They are used to caring for the scrapes and bumps of normal life, but not intense pain of children. How pain is addressed by health care providers will affect the course of the family's journey through the health care system and beyond. Documentation of expert

nursing practice with families is needed in the family literature. Additionally, such documentation can help novice nurses to see how family-nurse interactions are integral to expert nursing care.

Research Questions

The following questions are addressed at the end of the final chapter: How do nurses view families in the care of children in pain? In what ways do expert nurses involve families into pain care? When do nurses involve families in pain care? When do nurses not involve families in pain care? Does pain management involve emotional as well as physical pain for the family and/or child? Is there support for all levels of the Wright and Leahey (1990) family nursing theory in the data?

Chapter IV

Method

The study reported here explored expert nurses' involvements with families during the care of children in pain, using data from Gedaly-Duff and Holland (1994).This secondary data analysis took an exploratory, descriptive approach using grounded theory strategies for analyzing qualitative data (Stern, 1985; Hutchinson, 1986). Through constant comparative analysis themes were developed to describe the ways in which nurses interact with families to provide pain care for children.

Characteristics of Participants

Nine experienced nurses from acute care pediatric units in a Northwest metropolitan hospital participated in the primary study. There were eight females and one male with an average of 12 years experience in nursing and in pediatrics. Their education was baccalaureate except for one associate nurse and one diploma nurse. The sample (Gedaly-Duff et al., 1996a) included nurses who worked on two different acute care floors, each with approximately 18 beds. Children with a wide variety of diagnoses were treated. Admissions to the units included oncology, orthopedic, surgical, general medical, stepdown from the Pediatric Intensive Care Unit and Cardiac Recovery Unit, and children with chronic disease.

The data for this secondary analysis came from two sources: demographic questionnaires and focus group interviews which were audiotape and transcribed.

Demographic questionnaire. An investigator-developed demographic questionnaire was used to obtain descriptions of the participants. Questions were asked

about marital status, education and age of the participant and spouse, and the spouse's occupation, as suggested by Hollingshead (1975). Questions also were asked about length of practice as a nurse, in pediatrics, and in critical care. Finally, the nurses were asked to report their personal experience with pain, either their own, their children's or anyone close to them (Appendix A).

Small group interviews. Groups of two to six nurses who met one to three times provided group interview data. The group interviews created an atmosphere conducive to storytelling and promoted discussion about clinical episodes among the nurses. The groups were composed of nurses with similar levels of experience, to insure a collegial atmosphere rather than having some talking up or down to each other (Sandelowski, 1991; Tanner, Benner, Chesla & Gordon, 1993). Each interview session was limited to two hours (Gedaly-Duff & Holland, 1994).

Participants were prepared for the group interviews by asking them to think about when they knew a child was in pain. They were asked for a pain incident which was a story of success or failure in treating pain (Appendix B).

The interviewers were trained by the primary investigator. Each interviewer was prepared using the same guidelines and readings about running a focus group. To provide consistent all interviewers, all were given the " Researchers' Group Interview Guide" (Appendix C).

Recruitment procedures. Nurses were selected for participation on the basis of nomination by their peers and supervisors as expert nurses in pediatric care. Each nurse was given a written explanation of the study and each signed a consent form

(Appendix D). The interviews were conducted off the unit. The nurses were not paid for their time, due to unit policy (Gedaly-Duff & Holland, 1994).

Secondary Data Analysis Process

In the secondary analysis, the original transcripts were reviewed. The goal was to identify how practicing nurses described their interactions with family and children in providing pain care. The original audiotapes were used as necessary for verification. The Ethnograph program for data management was used. No further interviewing was done.

Grounded theory method was the inductive method. Data were examined using open coding, coding by themes and descriptions of situations, and by family focus level, using the levels of Wright and Leahey (1990). The data were analyzed looking for words that described nurses' and families' actions and for stories about pain and families. The data was sorted according to coding, and then by categories. Finally, major themes were developed from the categories (Hutchinson, 1986). This process was used to describe nurses' interactions with families and hospitalized children during painful situations.

The grounded theory method involves continuous constant comparative analysis of the data. In the current study, open coding was used initially to look at the actual words of informants, to prevent introduction of investigator bias. Memoing was done concurrently to document the researcher's thought processes. From open coding, more abstract terms were used to apply meaning and to conceptualize ideas. Family themes were then identified from the informants' descriptions. The investigator examined data and codes for similarities and differences when developing categories to describe nurses' interactions with families. In qualitative methods, the amount of data collected is

determined by the richness of the data and by the emergence of themes. When themes begin to be repeated, data analysis is terminated (Polit & Hungler, 1995). This study followed that qualitative approach.

Credibility of the data was examined by comparing interviews for similarities and differences. Then the family stories were compared and contrasted with the family theoretical approach of Wright and Leahey (1990) and the research literature was examined to note any similarities with identified themes (Catanzaro & Olshansky, 1988).

Human Subjects Review

An exemption from Human Subjects approval was obtained from Oregon Health Sciences University's Institutional Review Board for this secondary analysis. The original study (Gedaly-Duff & Holland, 1994) was approved by the Human Subjects Committee of the Oregon Health Sciences University (OHSU #3110) (Appendix E).

Nurses' identities were protected. All identifying information on the transcripts was removed from the interviews, as was demographic information. The demographic information was coded by number and any identifying information was stored in a locked drawer.

Chapter V

Findings and Discussion

This study examined nurses' interactions with families and children during pain management, using data from acute care nurses (Gedaly-Duff & Holland, 1994). The data were examined for themes describing how nurses interact with families in the management of children's. Pain management assessment was viewed as involving knowledge of medication, individual types of pain (surgical, procedural, disease and emotional) and developmental stages of children. The data revealed that expert nurses included the family in the assessment of children's pain and involved them in pain management. Nurses's beliefs about the family shaped their actions toward families and children. Four categories of approaches to family emerged from the data: a) nurses and families collaborating to provide pain management; b) nurses guiding pain management; c) families guiding pain management; and d) nurses and families with opposing views of pain management. Within these categories, the themes were congruent with Wright and Leahey's (1990) theory of family nursing: individual as focus, family as focus, and family as unit. These different views are illustrated below.

Nurses' Beliefs about Families

Their beliefs or philosophies about the family and families' views of pain and their relationships to pain management were discussed by these nurses. They held three philosophical views of families: a) families possess a unique knowledge of their children, b) nurses need to gain parental trust in their abilities to treat pain, and c) simultaneously understanding family as a whole and as a set of individuals is important. These three

viewpoints are discussed below under separate headings.

Families know their children best. Consistently, nurses spoke of families as knowing their children best. They believed that parents were the best source of information on their children. While family members might not know about behavior specific to surgical, procedural or cancer pain, they knew how their children normally acted or responded. Nurses used this knowledge to provide pain management. Parents were viewed as an integral part of "anything you do with the child."One nurse explained:

> I think you have to acknowledge that the parents know their kids the best and that what they tell you is pretty much true. You know, when they're telling you that this isn't the way their child behaves, you accept that instead of trying to convince them . . . is time and time again a parent will say "well this isn't the way my child usually behaves" and people [health care professionals] will just blow it off.

These nurses understood the importance of information from the people who knew the child best. It has been noted in the literature that parents are able to differentiate normal behavior from pain behavior even when there are no signs visible to nurses. Families are thus able to provide cues to nurses to understand the difference between normal and pain behavior (Tanner, Benner, Chesla, & Gordon, 1993). Parents have spoken to the need for health care personnel to acknowledge their relationships and knowledge of their children and, indeed, nurses value the knowledge that parents can provide to help them understand and treat children in pain (Ferrell, Rhiner, Shapiro, & Dierkes, 1994). Families know that they possess knowledge and they want to use that knowledge to provide appropriate pain

management to their children.

Gaining parental trust. These nurses viewed obtaining families' confidence and trust as part of providing care. In discussing successful pain management of children, the nurses said parents needed to believe that the nurses did not want children to be in pain and that they would listen to their concerns. One nurse said:

> And it's a real communication and trust between nurse and parent to be able for them to trust that you as a nurse truly or me as a nurse doesn't [sic] want their child in pain and truly I'm not going to blow them off.

Another nurse said, "I think it promotes parent confidence and that can do a lot for the child."

Developing trust between nurses and families is important because of the need for communication. When trust is not established and the family does not feel the nurse believes that the pain is real, there may be increased pain behavior and increased distress. The family also could leave a health care setting where they are uncomfortable and seek care elsewhere (Covelman, Scott, Buchanan & Rosman, 1990).

These nurses valued their relationships with families based on trust and good communication. When communication and trust existed, nurses felt that pain management went better. In a study of communication during painful procedures, Naber, Halstead, Broome, and Rehwaldt (1995) found that the most effective coping occurred when families and children were involved in meaningful conversation with the health care providers. Children were quiet and cooperative when communication was directed at the child and the parents were present. When the conversation was social or not directed

to the child, children become restless, and started to cry or resisted the procedure. Communication about the procedure built trust in the health care setting and caused less discomfort for families. There was an implied link between children's and parents' coping.

Families as a unit and families as individuals. These nurses said they needed to deal with the whole family in pain management for children. From past experiences, the nurses were aware of a range of beliefs about pain management. They recognized that every family has a philosophy about pain, each individual within the family holds beliefs about pain and different reactions also occur with different parent/child dyads. Some parents may hold that the child should be stoic and not take pain medication. Some parents may not want any pain to come to the child and will not let the child get out of bed. Families may be dramatic in painful situations and expect children to cry and moan. In some situations, children know that they can use pain as a means to an end (Maron & Bush, 1991). For example, children can use pain for secondary gain, such as getting a toy long wanted or the attention of an absent parent.

These nurses who had knowledge and skills in children's pain management, taught and negotiated with families about the best ways to treat their children's pain in order to provide optimal pain interventions. Nurses examined families as a unit and as individuals in order to provide a framework for pain management. One nurse said:

> When you're dealing with pediatrics, you're dealing with the whole family, . . . that's like unavoidable. And the people come from a wide, wide variety of experiences and philosophies about how pain should be managed and how the

> child should react to it. I mean, you get them all the way from they want them medicated for every little whine to "oh no, he's not hurting; he's fine."

Nurses recognized that different family members interacted differently with their child. Nurses looked at dyads within families to view the different approaches between mother/child and father/child. One nurse explained how children's actions depend on who is present:

> If they're just there with their mom and you're talking to them and you say, 'I'm going to put some pain medicine in your IV now and then we'll get up and go for a walk, and they're really, they may not say, they may not fight you at all but when their dad is there, then it seems like it's more . . .

The nurse implied that when dad was present, it might be difficult to get the child up to walk because the child would complain of pain. In contrast, the child did not resist as much in the mother's presence and the mother did not object to the child getting up. These nurses thus found that children acted differently with different parents. The nurses acknowledged that there were different dyads within the family and each one might interact differently. Nurses assessed individual parent beliefs about the child in evaluating how they approached pain management. The belief systems of each individual and family can help or hinder treatment of pain. Nurses identified these family beliefs and negotiated around them to provide pain management.

Nurses' philosophies about involving families in pain management of children formed a framework from which nurses interacted with families generally and specifically during pain management. Nurses described the importance of

a) acknowledging that families know their children best, b) gaining parental trust, and c) understanding the concept of family as a unit and family dynamics between family members as seen in father/child and mother/child dyads. Family views of pain and pain management were assessed by nurses in addition to knowledge of medications, types of pain and children's developmental stages.

Nurses' interactions with families and children during pain management

As noted above, expert nurses' beliefs about families are important in treating children's pain. With this as background, four categories of interactions with families emerged during data analysis. They were: a) nurses and families collaborating to provide pain management, b) nurses guiding pain management, c) families guiding pain management and d) nurse and families with opposing views of pain management. These categories are complex and fluid at times. Families may, at first, be opposed to the pain management plan, but when nurses educate families, their view may change and the family moves to another category. There may be chronic pain issues that have been treated successfully by the family in the past, but situations change. When the child has an acute pain crisis, nurses can guide management or nurses and families can work together to gain equilibrium for the children and the family.

Nurse and family collaborating to provide pain management. These expert nurses looked to families to provide the common ground for pain management. Nurses and families collaborated to establish common goals and worked together to achieve them. Nurses and families each felt that they had specialized knowledge to contribute to care and that pain management would be better as a collaborative effort.

Their collaborative efforts illustrated by a two month old who came in with an intracranial bleed. The nurse, parents and surgeon worked together to keep the baby comfortable. The nurse said:

> I have a good story . . . where everyone worked in synch, the parents, the nurse and the physician. It was a little two-month-old boy that I took care of in Peds I that had this vitamin K deficiency . . . He had a huge intracranial bleed. And the surgeon was Dr. P who believes that kids who have a neuro deficit have pain and that he can still assess them and still keep them comfortable. But we actually talked about this child's post op pain management with the dad and mom and [Dr.] P and they said "We just want him comfortable." They weren't concerned that he might have some developmental delay; they just wanted him comfortable . . . And the patient was out of that Peds ICU [Pediatric Intensive Care Unit] in two days, two days . . . It worked really well.

The family, physician and nurse worked together to manage pain. The usual course of pain management with a neurosurgical patient does not include medication that alters neurologic response on the assumption that changes in neurological status will then be easier to assess. The doctor, though, worked with the family and nurse to find a medication that still allowed for proper assessment. The discharge from Peds ICU within two days indicated that with adequate pain management the child was stable enough to be transferred. The main concern of the family was pain control. However, the nurse viewed the child in a larger way, as evidenced by her reflection on the possibility of developmental delay from the bleed. The nurse, family and doctor collaborated on

management of the surgical pain but the nurse was also aware of other concerns that could come up later.

Nurses and families worked together to provide care when the child was afraid of pain treatment. Nurses and parents collaborated and used their joint authority to treat pain. One nurse discussed parents' right to make decisions for their children:

> I think people used to think that they were going to get a shot if they said they hurt. And so part of my thing is then to say, 'You won't even know we're giving you medicine providing it's IV or something,' . . . And you're not going to make them hurt to get pain relief. And a couple of times we had to go over the child with the parents' permission . . . and give them some anyway.

This nurse tried to educate the child to take pain medication, explaining that she would not cause more pain. When that did not work, the nurse consulted with the family and gave the medication against the child's wishes but with the family's permission. The nurse included the family in decision making and acted with their assent. Both the nurse and parents recognized the child's fear of needles and acted jointly in the best interest of the child. She understood that parents have societal expectations to make decisions for their children and consulted with the parents for that reason.

One nurse told a story about her inability to assess pain because she did not know the child. She looked to the family to provide information on the child's usual state. The nurse said:

> It's like 'can you tell me if there's an owie' and they won't even look at you. Or you walk in the room and they just scream. And so a lot of it is relying on the parents' interpretation of their child's discomfort to some degree.

The nurse wanted parents' interpretation of their child's behavior. The nurse did not try to guess the reason the child was acting as she did. The nurse consulted with the family in order to acquire parents' special knowledge about their child. The nurse might have been unable to ascertain what was a pain sign or what was a normal distress sign for this child without parents' knowledge.

These examples illustrate how nurses collaborated with families. Nurses educated parents and discussed plans with them, and implemented plans with parents' permission. Nurses also consulted with parents to understand children's reactions before deciding on a pain management plan. Nurses viewed families as a unit.

Nurses guiding pain management. Nurses guided pain management by assessing children and families to understand their needs and provide appropriate pain treatment. They used information obtained from families to treat children's pain. One nurse said:

> You know, asking the parents what the norm is. And you also have to think about what they've had done [type of surgery or procedure].

Nurses drew on parents' knowledge of their children and their own knowledge of different types of pain in children to plan treatment. They merged parental knowledge with nursing knowledge to provide individual pain management. However, nurses did not collaborate with parents in the decision making about pain management.

When parental knowledge was absent and the child was unable to provide information, pain management was harder. Nurses acted on their experience and knowledge of pain in children, but they felt that pain management would have gone better with family input. One nurse said:

> I was asked to look at a patient on [floor] that was CP [cerebral palsy] and had some, didn't have a surgical procedure, but he had something medical wrong. And they were trying to decide whether he was indeed in pain or just agitated and we literally couldn't make the difference because the mother was unable to provide us with cues of what was normal because she really wasn't into the child's normal state. So we just treated and he was covered.

This mother was unable to help the nurse interpret the child's behavior, so the nurse did not know the boy's normal behavior. The nurse was frustrated because she did not know whether the treatment was effective for this child. This illustrates how important families' input is for understanding children's needs, especially with nonverbal children. Nurses look to families to understand children's usual pain responses and normal behavior.

One nurse said that she collected information from the family on the child's pain in a variety of ways. She used this information to understand the child and used the child's interactions with the family to assess the child's pain intensity. She used parents' information to evaluate the effectiveness of pain interventions. This nurse said:

> I have another child that had an abdominal tumor resected and she was probably somewhere between 12 and 16 months and she had on an epidural fentanyl drip. And the day after surgery, she was in the playroom, you know definitely, if you

> asked her parents, not 100 percent, but boy she was right up there like 80 or 90 percent and then it was wonderful. It was nice to see a kid able to function at that level after having such a procedure. She ambulated with assistance, she was able to eat, she was able to interact with her parents.

The nurse compared her knowledge of toddler development with the parents' knowledge of her normal behavior to evaluate the effectiveness of the pain treatment. The nurse's observations of the child's eating and drinking and the child's interactions with her parents were part of the pain assessment. The nurse, however, made no reference to including the family in decision making.

Another way nurses treated children's pain was by educating families about narcotics and addiction. Parents, because of their misconceptions about opiods, sometimes resisted their use in pain treatment. One nurse said:

> There's a lot of misconceptions with the families and the narcotic issue . . . Because that's what the parents, just because for years, narcotics have had a bad rap on, you know, it's like it's too easy to get addicted and all that kind of thing so it's like you have to reeducate or educate in general, the public . . .

Families' exposure to television and school campaigns against drugs was transferred to the hospital, where narcotics are the usual way of treating surgical and procedural pain. Nurses frequently taught families the medical reasons and appropriateness of using narcotics. Through education of families, nurses were able to guide pain treatment to include narcotics.

The perspective illustrated in these examples saw the individual as focus of care (Wright & Leahey, 1990). Nurses' pain treatment focused on the child, and parents were a source of information or were used as an instrument. Parents' knowledge of their child's normal behavior was used to evaluate the effectiveness of pain treatment. At other times, nurses educated parents to facilitate the use of narcotics.

Families were sometimes nurses' primary focus in treating children's pain. Children's pain affected their families and nurses recognized and treated parent anxiety related to their children's pain. These nurses discussed decreasing parent anxiety by developing and maintaining trust, and educating families when they asked for inappropriate medications.

The families had treated children's common pain from scratches to falls. However, parents did not know how to relieve pain from surgery or procedures. They sought nurses' knowledge about children's pain. They wanted to know if their children were having the expected amount of pain, if they were recovering at the appropriate rate and if they were tolerating pain in a normal fashion. When parents were overly concerned and anxious, nurses intervened with the families to reduce their anxiety. Nurses acted on the assumption that decreasing parents' anxiety would decrease their children's anxiety.

These nurses discussed how families' past experiences may have influenced their present uneasiness. One nurse explained:

> Sometimes too, you don't know if parents when they're perceiving their kids pain, is that something that happened to them when they were a child too and

they're just trying to sometimes project . . .

Nurses speculated about how parents' life experiences affected their perceptions of their children's experiences. Nurses separated parents' anxiety from children's pain. They recognized that parent anxiety could be caused not only by children's actual pain but also by parents' perceptions and past experiences.

Relieving children's pain did not always reduce parental anxiety. Sometimes families were anxious because they did not know what was normal for a particular situation. Pain from surgery or procedures was often a new experience for families. They learned from nurses what to expect about pain after surgery so they could evaluate for themselves how their children were coping with the new type of pain. One nurse said:

> The mom knew she [the child] was in pain, but she wanted to know if that was normal for this type of a problem. It's like they wonder if the child's overreacting or just want to know that it's normal.

The nurse listened to the mother's concerns and questions, then the nurse educated the mother and reassured her that the child was reacting in the expected manner. The nurse thus treated the mother's anxiety without doing anything directly to the child.

Some parents requested pain medication inappropriately. One nurse related the following:

> A lot of it's a matter of education . . . you just give them concrete information about what you are looking for and how what you are seeing doesn't jive . . . you know how someone acts when they are typically uncomfortable. And sometimes if you can just point that out to the parents, they kind of relax a little bit.

Again, by teaching family members what to expect and how to evaluate pain behavior, the nurse helped parents relax and be less anxious. The nurse identified the issue of parents' discomfort and the need to treat it separately from their child's pain. By educating the parents about pain symptoms, the parents' anxiety was lessened. This occurred independently from treatment of the child's pain.

The following example illustrates the long term outcome of not treating a mother's anxiety. One nurse said:

> I had, this isn't really in pain, but we had a patient at another hospital I worked with, that had BPD [bronchial pulmonary dysplasia], a premie with BPD, and spent quite a long time with us, and there were a lot of issues the mom had that were never resolved. They just ignored her and ignored her. She went home, the child got sick, like two weeks later, she refused to come back to our hospital and he ended up dying because they went to a smaller community hospital that wasn't able to deal with how sick he was at the time.

The mother's issues were not addressed. The nurse observed the mother being ignored and implied that this lack of attention to the mother's needs may have contributed to the child's death. The nurse speculated that if the mother's concerns had been addressed effectively, the outcome might have been different. Thus, the nurse reflected on the power of emotional pain caused by lack of parent trust and on the importance of treating the mother as well as the child.

As Broome and Endsley (1989) have pointed out, parents anxiety is part of children's pain response. In these examples, nurses treated parents' reactions to their

children's pain; they treated parents independently from their children. The family perspective was, thus the family as focus (Wright & Leahey, 1990). The primary source of pain was from anxiety and was treated through education and reassurance. The connection between parent emotion and child well-being may have its roots in attachment theory. According to Bowlby (1988), with secure attachment, the parent is readily available, sensitive to her child's signals and responsive when the child seeks protection, comfort, or assistance. When the child looks to the parent for relief of pain and the parent is unsure how to treat it, the parent becomes anxious. Nurses recognized this bond between child and parent and intervened to reestablish the bond.

Nurses also treated children's pain through awareness of the effects that the interactions between family members had on the whole family. Nurses considered the family as a unit. One nurse told the story of a dying child and his mother. The child was on a PCA (patient controlled analgesia) pump. The pump administered a basal rate, i.e., a continuous infusion to cover the constant pain, and demand rate, i.e., a button that a parent or child could push that gave an extra dose when the child had breakthrough pain. The child used the button for pain medication until he became too ill. As the child was less able to push the button to give his own medication, the basal rate was increased. The bolus dose was still used by nurses when care was given, to cover the increased pain. The mother also gave bolus doses. The nurse went on to say:

> She would press that button a lot even though he was like totally asleep and then every time she was going to smoke, she would always push the button that made her feel better on leaving this dying child's bedside. And after a while what they

> did to treat that, they realized that mom needed to . . . they realized that mom needed to push the button so they decreased the dose so that it was so low. . .

The nurse recognized the parent's need to protect the child. While the nurse could not stop the boy from dying, the nurse helped the mother protect her child from pain. Instead of asking the mother not to give bolus doses, the health team changed the bolus dose to a safe amount. Thus, the mother took an active part in her child's care and fulfilled he role as a mother. Nurses recognized the emotional pain of the mother and allowed the mother to maintain a bond with the child through management of technology. The family unit was recognized.

Nurses observed families becoming emotionally upset because of pain. One nurse explained:

> The kids escalate and be screaming the whole time, out of control, and then the parents out of control, sometimes you can calm that situation down real quickly if they (the family) know that you are going to get them something and it's going to work and you're going to do it time efficiently; you're going to be back when you said right away. Those are the things in my experience in general, seemed to have really helped. And then help them develop some other coping mechanisms (other than medicine) that they could do to support themselves.

The nurse spoke of the children and their families going out of control. She then worked with the family as a whole to calm the situation. She mapped out for the family what she was going to do. She stressed the importance of following through so that the pain was successfully treated. She then used this positive relationship to help families maintain

control. The nurse viewed the family as a unit and tailored her interventions to treat the whole family.

One last example in which a nurse viewed the family as a unit involved a reflection by a nurse on the effect that families and children have on each other. She said:

> And they really have a big effect on the children too. If they're thinking positively or they're understanding why they need to encourage activity or whatever, then that helps the child get well better and it's really important. It seems that . . . how the parents cope unlocks how the kids cope. And if you see dysfunctional patterns in how the parents cope, then you can just immediately assume . . . this goes hand in hand.

Nurses thus had a sense of the family as a whole. They also perceived families as a system while acting with the various dyads in the family -- mother/child, father/child, mother/father and sibling/sibling. This nurse, in reflecting on her practice, recognized that there are patterns of coping within families. McGrath (1993) told a story of a family whose son had diabetes; the child was not coping well with the painful procedures involved, with injections and finger pricks. The staff noted that the parents were also distressed especially the mothers. The family was taught to cope by relearning finger sticks on a teddy bear. Learning coping skills together helped the family manage the painful aspects of diabetes. These examples demonstrate how nurses treat children's pain from the perspective of family as unit (Wright & Leahey, 1990). The family intervention was for several members and their interactions. The nurse looked at the parents' response to the child's pain. She looked at the child and assessed his ability to cope. She then

developed a plan to include the family as a unit to cope with the painful procedures.

Family guiding pain management. At times, families in this study had very definite ideas about pain management. Some knew their children well and had expertise in caring for their children's pain. They had found ways to treat pain or discomfort. Nurses did not need to manage pain, nor did families need to consult to achieve pain management for the child or the family. Other families had definite ideas about pain management that didn't agree with nurses' views. Since no harm would occur, nurses went along with the family's plan.

One nurse described how a mother and son dealt with pain during a procedure. Although pain medications were given, the main pain management occurred between the mother and child. They had developed a way to work through the pain of the procedure. The nurse explained:

> She did really well. They just curled their heads together and she was really supportive, did what she needed to do. She could be divorced a little bit and just help him. She didn't watch (the procedure) and so kept talking him through the situation.

The nurse was impressed with the mother's ability to help the child through the pain experience. In this instance, the mother guided her child's pain treatment.

> Another family guided the pain treatment related to chronic pain. The nurse said:
> So the mom also helps be the care giver here and I usually really rely on them for like how, to help me assess pain and also it helps, I think, the parents a lot if they can show you like 'This is how I move them at home and this is how- this will

make them feel better' and just allow them to do that kind of stuff.

The nurse sought the family's special knowledge of how to move the child and other ways to comfort and treat the child's pain. She also stated that having the parent provide care helps the parent. It was implied that the mom needed to provide care to the child while they were in the hospital. The nurse looked at the mother/child dyad to assess what was happening.

Nurses acknowledged that families of children with chronic pain or comfort problems possessed expertise to provide pain management for the chronic pain. Families knew children and their pain from having lived with them on a day-to-day basis. The nurse did not possess that knowledge.

One nurse talked about families who insisted on medicating children more than the nurse considered necessary. The nurse said:

> So they're saying that they have a lot of pain and I know medically that they're not getting an overdose, then they're still, their vital signs are still stable and stuff, if they want that extra dose, fine. It's not worth creating or chipping away at that relationship you're building with them over that thing and I've found that most people get real reasonable about that. Once they really feel "like okay, if I say they're in pain and they [nurses] respond"... it's again a trust issue relationship thing.

The nurse weighed the effect of pushing her point of view and decided that it was better to give more medication. The nurse continued:

> Because a lot of their demands are made based on no information or misinformation and so sometimes if you can just educate them.

The nurse chose to establish a relationship with the family. She allowed them to guide the pain management, at first. She then established a way to educate the family. Through education, the nurse guided pain management. The nurse acknowledged the anxiety of the family and chose to go along with the family before trying to change the family's viewpoint.

Nurses and families with opposing views. There are times when the health care establishment conflicts with family views of the best way to treat their child's pain. One nurse told of a family whose six-month-old had cardiac surgery. The family had not wanted the baby to have surgery but they were threatened with involvement by Children's Services. The nurse said:

> Natural, happy family that was thrust into the world of medicine and the two didn't gel very well. And it was difficult giving the child plain Tylenol because that's not what the family believed. And I don't know that we actually helped establish a trusting environment there because they were totally overwhelmed by the world of medicine.

Instead of Tylenol, the family wanted to use a herbal medicine called Willebark. The nurse gave Tylenol when the parents weren't around. The nurse discussed the idea of not being able to build a trusting environment because of the overwhelming nature of the situation and the parents feeling that they lacked any control over the situation. The nurse felt that Tylenol was a place where the family could take a stand and assert some control.

The nurse gave the Tylenol because she felt that the benefit to the child was greater than the harm to the family.

Another nurse described families and children not wanting to walk because of pain. The nurse knew that after surgery children need to get up and move around so complications, such as pneumonia or bowel problems, don't occur. She said:

> Because in a lot of times with kids our age (one to three years), it's like they'll say no, they don't want to walk and I don't think you can really build up a trust thing; it's more of a "Sorry, you don't get a choice. At this point, you need to do this and I'm going to give you medicine to make it not feel as bad when you get up and walk, but you do have to go walk to this point and back again."

The nurse listened to the family and the child about the level of pain and weighed the damage that would be done if the child did not walk. She felt that the good that came from walking outweighed the harm that occurred to relationships.

Complexity and Fluidity

Nurses have a combination of special knowledge and expertise about children, families and pain. Expert nurses, in treating children's pain, synthesize information about medications, nonpharmacological interventions, types of pain and child development along with family influences. This synthesis is a complex, fluid process. Nurses must be aware of the intricacies of family dynamics, family philosophies and individual beliefs. Each family presents with different problems and solutions.

In the following story, the nurse approached a situation using a complex and fluid manner. She explained:

> I had one instance where the parents, I can't remember if they were married or not, but they were together. And I had a little girl that was like two and two and a half that had maybe a club foot relief, some kind of orthopedic surgery, but it was a short stay. She was only supposed to stay like overnight or two nights. And the dad was real, real anxious whenever she would cry, he was just like "Well when did she last get morphine? She needs morphine." And I knew that she was supposed to get ready to go home and so was trying to negotiate how things were going and was she ready to change to PO pain medicine and stuff and her mom was much calmer about it. And you know, it was just a lot of education.

The nurse examined the situation by looking at the family as a unit and at the individual members. The child was close to discharge and the nurse wanted to move her to oral medication. The father was afraid that the child was in too much pain and needed IV medication still. The mother appeared calmer to the nurse and open to education about medication management.

The nurse explained about home care to the family and negotiated with the mother on pain management. The nurse continued saying:

> Well these are the kinds of things we look for and we're giving the medication regularly and some of it was a trust thing too. You know, I said to her mom "Now if this doesn't work; I'm more than willing to come back with the IV medication so that she is comfortable, but we do need to give it a certain amount of time to work" and all that.

The nurse explained the plan. She realized the need to maintain with the family. She also

educated the mother on what to look for at home. The father was still present. The nurse continued:

> And she actually ended up sending the dad away because she was the one that was going to take care of the little girl at home any how and he was distracting her more than the child was.

The nurse assessed the family and worked with the person who was the primary care giver. The nurse did not make the decision for the family on who should be present. The decision to exclude the father was made in the family. The nurse worked with the mother but still considered the father. She said:

> And you just got the feeling that something happened to him at some point in his life that made him just absolutely hyper about this issue and the child being in the hospital. Or maybe something happened to the little girl that, but you could tell it was a very emotional issue for him.

The nurse reflected on the father's anxiety about his daughter's pain. The nurse examined possible reasons that the father was so emotional. There was no indication in the data whether there were interventions with the father, however.

The nurse continued to work with the mother and child to insure that they were ready to manage the pain at home. The nurse said:

> And yet, the mom, you know, we discussed it, she was part of the decision making process and the little girl did progress to a point where the mom felt comfortable taking her home.

This story illustrates the complexity of situations in pain management. The nurse needed to be fluid in her approach and flexible in how she worked with the family. The nurse provided basic instruction for the family but also went beyond. She recognized the family as a unit and made no decisions on who should be included or excluded. She examined the dyads within the family- mother/child, father/child and mother/father. She described her assessment of the family and theorized about the father's reactions to his daughter's pain. She proceeded in a nonjudgmental fashion to move this family from the hospital to home. The story illustrates the multiple layers that expert nurses assessed and used to provide care.

Chapter VI

Summary and Conclusions

This study explored how nurses interacted with families and children during pain management. The findings were based on a secondary analysis of data from focus groups of experienced acute care nurses (Gedaly-Duff & Holland, 1994). The original data were collected from 9 nurses who were interviewed one to three times in focus groups consisting of two to six people. The nurses were interviewed to learn how expert nurses learn to treat pain in children. One of the findings was that nurses consistently mentioned families when describing pain management. The study reported here expanded on the family theme.

Expert nurses involved families in pain management when families were present. There were four ways identified in which nurses interacted with families: a) nurses and families collaborating to provide pain management, b) nurses guiding pain management, c) families guiding pain management, and d) nurses and families with opposing views of pain management.

How do Expert Nurses View Families in the Care of Children's Pain

Nurses held the following basic beliefs about families: a)families know their children best, b) gaining parent trust is important to nurses in order to provide pain management, and c) the family is a unit whose members are individuals with varying beliefs about pain management.

How do Expert Nurses Involve Families in Children's Pain Management

Nurses involved families in pain management in four ways. The first was nurses and families collaborating in pain management. Nurses and families shared information and agreed on a plan of pain management working as peers. The second was nurses guiding pain management. Nurses used their knowledge and skills to provide pain management. Families provided knowledge of their children to nurses, but nurses decided on the course of pain management. Third was families guiding pain management, in two ways. Families were used to the pain that their children were experiencing and had the expertise to manage the pain. Families also had opinions on pain management which did not match the way nurses usually provided care, but since no harm would occur, nurses went along with the families to maintain a trusting relationship. Then they started education in pain management later. The fourth category was nurses and families with opposing view of pain management. Nurses assessed families and their ideas about pain management. When those ideas were considered harmful for the children, nurses acted against the wishes of families. Nurses did not exclude families from caring for their children except for decisions about pain treatment.

When Expert Nurses Involved Families in Pain Management

Nurses felt that families were an essential part of pain management for children. They tried to include families in one way or another, depending on the focus of pain management. There were no incidents when families were totally excluded. Nurses assessed families for ways to involve them; the amount of involvement varied depending on how families' opinions meshed with nurses' assessments of the situation.

Management of Emotional as Well as Physical Pain

Nurses treated the emotional pain of families along with their child's physical pain. When families were anxious or fearful, nurses recognized the effect of anxiety or fear on families and children. Nurses intervened with families by listening to them, identifying their concerns and working to eliminate the causes of anxiety.

Support for Wright and Leahey's Family Nursing Theory

Three of the four levels of Wright and Leahey's (1990) theory of nursing of the family were found: individual as focus, family as focus and family as a unit of care. All of these levels were evident when nurses guided pain management. In three categories (nurses and families collaborating to provide pain management, families guiding pain management and nurses and families with opposing views), families were viewed as the unit of care. When the individual was focus, nurses viewed families as the background for pain management. The child's pain was treated and the family was involved as an instrument to manage pain or as a roadblock to care. The family was the focus when the child's pain was in the background and the family was the main focus of pain management. When the family was viewed as a unit of care, the family as a whole was seen as affected by pain. Nurses treated the whole family and the various dyads, e.g. mother/father, parent/child, within the family.

Nurses decided on pain management depending on the pain focus. If the families were distressed, nurses looked at the family as a unit in managing pain. If the children were in pain and unable to communicate, nurses looked to families for information.

Implications for Practice and Education

This study looked at actual stories and reflections of nurses to examine what occurred in their practice when treating children's pain. Expert nurses' views of families and how they involved families in pain management were examined. Because this was a secondary analysis, participants could not be reinterviewed if clarification was needed. It also was not possible to take the findings back to the participants to verify the results. The sample contained only nine participants so saturation was not reached. Nevertheless, this documentation of what expert nurses actually do in pain management can be used to teach novice nurses ways to work with families. It will also give nurses a way to explain to the public what nurses do. As the story of the nurse and family collaborating on pain management of a two month old showed, the cost of a pediatric intensive care stay was reduced when the nurse had time to plan with the family.

Implications for Further Theory Development in Family Nursing and Research

This explication of practice can be used to strengthen or modify family nursing theories. Studying expert nurses in practice brings the theories out of academia and into the main world of nursing. The implications for further study are threefold. First, by analyzing Gedaly-Duff et al (1996a & 1996b) data generated from critical care group and the health maintenance organization (HMO) setting, categories identified can be expanded, refined and/or verified. These data sets are rich with nurses' stories of their interactions with families, from vantage points different from those of acute care nurses. Second, expert nurses could also be interviewed using the findings of this study to generate research questions. Their answers would be used to verify, disprove or expand

findings.

Third, families and children who have interacted with nurses during pain management could be interviewed and questions based on nurses' perceptions of their interactions with families. This information could tell nurses if what we think we are doing is really occurring.

Conclusions

The pain literature speaks of parents and children but often lacks a family framework. Nurses involve families in their daily practice and they are concerned about families and subsystems of families.

Families are an integral part of treating pain in children effectively. Families know children best. Families are able to tell nurses about their children's normal behaviors and past pain behaviors.

These nurses found families' history important in helping to understand the reactions of families and children to pain situations. Nurses used the information to form and refine interventions.

Nurses have profound skills based on their knowledge and experiences with the pain of children and families. When expert nurses treat children and families, bad situations are less likely to occur. When nurses treat parent anxiety, they prevent the situation from getting out of control. When the family's concerns are not addressed, the probability of a positive outcome is greatly diminished. Expert nurses provide complex and fluid approaches to families and their children in order to give high quality care.

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Glossary

Family: Family is self-defined by its members. It is any group of two or more people who rely on one another for emotional, physical, and/or emotional support (Hanson & Boyd, 1996).

Grounded theory method: A research method used to search out empirically grounded factors or to relate factors that pertain to the research problem at hand; not doing theory development but description and themes (Stern, 1985).

Pain: 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, Subcommittee on Taxonomy, 1979); an unpleasant sensation, occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder (American Heritage Dictionary, 1975).

Secondary analysis: When a researcher tests new hypotheses by using raw data collected by someone else (Jacobson, Hamilton, & Galloway, 1993). In the present study, the intended definition of secondary analysis was expanded to include a researcher identifying and describing new information by using raw data collected by someone else for another purpose.

Appendix A

Demographic and Descriptive Questionnaire

Nurse Demographic and Descriptive Questionnaire

IDENTIFYING DATA

Subject's Name: _____
(Last) (First) (M.I.)

Subject's Address: _____
(Street)

_____
(City) (State) (Zip)

Phone Numbers to reach respondent: Home _____ Work _____

Best time to call respondent for follow-up interview: _____
(please specify am or pm)

DEMOGRAPHIC AND DESCRIPTIVE QUESTIONNAIRE

1. Age of subject _____

2. Birthdate: Year_____ Month_____ Day_____

3. Sex of respondent: a. female_____ b. male_____

4. Age of spouse (partner)_____

5. Subject's Occupation_____

6. Spouse's Occupation_____

7. Educational level of subject. (Please circle the appropriate year/s.)

   Grade School: 1 2 3 4 5 6 7 8 High School: 9 10 11 12

   Business/Vocational/College: 13 14 15 16

   Graduate School: 17 18 19 20 21 22

8. Education level of spouse. (Please circle the appropriate year/s.)

   Grade School: 1 2 3 4 5 6 7 8 High School: 9 10 11 12

   Business/Vocational/College: 13 14 15 16

   Graduate School: 17 18 19 20 21 22

9. Ethnic Background: a. Caucasian____ b. African-American____

   c. Hispanic____ d. Asian____

   e. Native American____ f. Other_____
   (Please specify)

10. Religious Affiliation: a. Protestant____ b. Catholic____

    c. Other_____
    (Please specify)

    d. None____

11. Marital status of subject:

    a. _____ Married or stable partner

    b. _____ How long?

    c. _____ Divorced and remarried

    d. _____ How long in new marriage?

    e. _____ Widowed and remarried

    f. _____ How long in new marriage?

12. Nursing Education:

    a. Diploma ____

    b. Associate Degree ____

    c. Bachelor Degree ____

    d. Master Degree ____

    e. Bachelor Degree in Nursing ____

    f. Master Degree in Nursing ____

    g. Post Master Degree ____

13. Years of nursing practice _____

14. Years of practice in a critical care unit _____

15. Years of practice in PICU _____

16. Years of practice in CCR _____

17. Years of practice with children and families _____

18. Work shift

    a. day

    b. evening

    c. nights

    d. other

19. Nurses with children?

a. yes ____

b. no ____

c. no response

20. Ages of children

_____

_____

_____

_____

_____

_____

21. Children had painful experiences?

a. no ____

b. yes ____ Please describe:

22. Other family experiences with pain?

a. no ____

b. yes ____ Please describe:

Appendix B

Preparation Guide for Small Group Interviews

Preparation Guide for Small Group Interviews

As part of your participation in this study, you will be involved in small group interviews. There will be 4 to 6 nurses in these groups, some of whom will be from the unit in which you are employed. All of the nurses in your group will have approximately the same amount of intensive care experience.

In these groups, each of you will be asked to describe a clinical situation concerning a child's pain experience in which you made a difference. We hope to have you tell us two to three such stories during the group interviews. Sometimes you may decide ahead of time which patient situation you would like to describe. Other times you may find that during the interview, someone else's situation may remind you of one that you experienced. Either kind of situation is fine.

Before your first group interview, we ask that you reflect on your critical care practice over the last year or so and select an incident in which you feel you made a difference. Any of the following might be situations that stand out for you and are quite appropriate to share:

1. An incident in which you feel your intervention really made a difference in a child's pain outcome, either directly or indirectly (e.g., by helping other staff members)

2. An incident that went unusually well

3. An incident in which there was a "breakdown" (i.e., things did not go as planned)

4. An incident that is very ordinary and typical

5. An incident that you think captures the quintessence of what nursing is all about

6. An incident that was particularly demanding

In the group we will ask you to describe the situation in story form, filling in as much detail as you consider necessary for someone else to understand your intentions, fears, feelings, as the situation unfolded. We will ask how past experiences with pain, either in your practice or personal/family life, may have influenced you. It helps to recount how you were thinking and feeling before the outcomes of the situation were clear, since this is the most accurate way of accounting for the uncertainty that exists in any changing clinical situation.

We will ask you the questions to probe for the following kinds of information. You may not remember it all, and that's okay.

1. The context of the incident (e.g., shift, time of day, staff resources)

- OVER -

2. A detailed description of what happened including as much dialogue as possible

3. Why the incident is critical to you

4. What your concerns were at the time

5. What you were thinking about as it was taking place

6. What you were feeling during and after the incident

7. What, if anything, you found most demanding about the situation

8. What you found most satisfying about the situation

During the interview, we will also encourage others to ask you questions to clarify the nature of the situation. This is because few of the investigators have had recent experience in critical care nursing, and we may miss probing for what may be quite important information.

The interviews will be tape recorded and transcribed. We will attempt to review the transcripts in between sessions, so that we may ask for further clarification.[1]

[1]This preparation guide was adapted from similar questions by Dr. Tanner (Personal Communication, 1993).

Appendix C

Researcher's Group Interview Guide

Researchers' Group Interview Guide[1]

The group interviews will begin with the following questions (the individual interviews will be adapted from these questions):

1. Describe an instance in which you knew a child was experiencing pain, and/or tell me of an experience you had dealing with a child's pain in which you learned something (elicits the subject's view of the "story").

2. How did you know the child was having pain? Prompts will focus on location, duration, frequency, intensity of pain. (Elicits the cues and informational technology that were used to interpret the pain.)

3. How did you learn to handle the situation in this way? (Elicits if the nurse learned this by watching other nurses, or from patients or their family.)

4. How was the situation handled? (Elicits nurse's perceptions of the pain treatment initiated, or barriers to treatment, or ambiguity of the situation.)

5. Were there past personal or family experiences that influenced your personal handling of the situation? (Elicits if the nurse learned about pain from personal and family life events.)

6. What led you to decide to handle the situation in this (these) ways? (Elicits the reasoning the nurse did.)

7. Who initiated the pain treatment? The child and his family, or a health professional? (Elicits the people identified as concerned about the child's pain.)

8. What did the child or family do to cope with the pain? (Elicits nurse awareness of family involvement.)

9. What was the effect of the way the pain situation was handled? (Elicits outcomes such as ignoring pain or redefining the situation.)

10. Were there things you would change and were there things you would keep the same? (Elicits a summary of the most important factors in the situation, processes, and outcomes.)

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[1]Interview guide was adapted from similar questions used by Drs. Tanner and Tilden (Tanner, 1992, Personal communication; Tilden, 1991).

Appendix D

Consent Form with Written Explanation

Nomination Form

05/10/94
ORS#: 3110

Oregon Health Sciences University

Consent Form
(Staff Nurse)

TITLE: Acute and Critical Care Nurses' Experiences with Children's Pain (Acute Phase)

INVESTIGATORS: Vivian Gedaly-Duff, DNSc, RN. telephone: 503-494-3866
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PURPOSE: The purpose of this research study is to interview acute care nurses who have consistent interaction with non-verbal children who may be experiencing pain associated with disease, trauma, or procedures in order to learn the nurses' experiences, reasoning processes and outcomes as they manage a child's pain.

PROCEDURES: Nurses who volunteer will be asked to fill out a demographic and descriptive questionnaire. This should take about 10-20 minutes. Nurses will be clustered into groups of 3-6 and will be asked to talk about a clinical episode of a child experiencing pain. These sessions will be no more than 2 hours and may be conducted up to three times for each group. Each session will be audiotaped. The groups will be made up of nurses of similar levels of practice. As the investigators continue in their analysis of the data, we plan to come back to you to verify our interpretations. The time involved with this part of the study is part of the 3 group interview periods.

You may be one of five nurse who will be selected for 3 one hour observation periods. This observation time will be audiotaped in order to help the observer make accurate field notes. The observation time will be during the first two hours of the work period in order to capture the intense initial assessment and nursing planning. After the observation, the observer may ask you to clarify or explain items that occurred during the observation. In addition, at a convenient time for both you and the interviewer, you will be asked questions exploring your own and your family's pain experiences; and how you learned to care for pain in your practice. Some of these questions may be of a sensitive nature. This interview will take approximately one hour.

RISKS AND DISCOMFORTS: The investigators are not aware of any risks for you other than possible discomfort over recalling and talking about experiences, processes, and outcomes of children in pain. You may perceive that you are being evaluated on the care you administered to the children.

BENEFITS: You may not experience specific personal benefits from this study; however, as a professional nurse, you will be contributing to the knowledge in managing a child's pain experience.

CONFIDENTIALITY: All data will be kept in a locked file cabinet. The tape recording of the interview will be typed by a transcriptionist who will sign an agreement to keep all the information confidential. After the tape is typed, it will be erased. Neither the name nor any identity of the participants will be used for publication or publicity purposes.

To insure nurses' anonymity, consultants, Drs. Tanner, Donovan, and Imle, will not serve as interviewers for this study, nor will they read any transcripts until all interviewees' responses have been coded to protect their identities.

Because the proposed study is about nursing judgement and practice, the investigators feel ethically that they are obligated to uphold the Oregon Nurse Practice Act. Therefore, in case that an incident of gross negligence and/or harm to patients is identified, as described by the Oregon Nurse Practice Act (1985), the issue will be discussed with the individual involved and the appropriate supervision and/or agency.

COSTS: There are no costs for you, the participant, for participating in this study.

LIABILITY: The Oregon Health Sciences University as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please call Dr. Michael Baird at 503-404-8014.

You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with the Oregon Health Sciences University. You will receive a copy of this consent form. Dr. Gedaly-Duff (telephone: 503-494-3866) or Ms. Holland (telephone: 503-494-5303) will answer any questions you might have about this study.

Your signature of this consent form indicates that you have read the above information and you agree to participate in this study.

Thank you for your willingness to participate.

_____	_____
participant	witness
_____	_____
date	date

A000016F.VG1/062994

Nomination Form in Preparation for Small Group Interviews[1]

(date)

Oregon Health Sciences University
School of Nursing
3181 SW Sam Jackson Park Road
Portland, Oregon 97201-3098

Dear _____(name of nurse)_____,

We are planning to use the Critical Care Units caring for children as the setting for our research project, "Critical Care Nurse's Experiences of Children's Pain." Our investigation will include observation and interviews of nurses in the practice setting. We are asking that you identify, from your observations and close working relationships, the registered nurse clinicians who have advanced skill and knowledge in delivering direct patient care in the Critical Care Unit.

Please print the names of the nurses you have identified on the attached blank form and mail it in the enclosed self-addressed, stamped envelope. The nurses you identify may be approached and asked to voluntarily participate in this study.

We thank you for your time and consideration.

Sincerely,

Vivian Gedaly-Duff, RN, DNSc
Principal Investigator

Enclosure

VG-D:vn
A000022F.VG1

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[1]Nomination form adapted from a similar survey used by Jacavone and Dostal (1992).

Appendix E

Original Human Subject Approval and Exemption for Human Subjects

from Oregon Health Sciences University

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787
Institutional Review Board/Committee on Human Research

DATE: April 29, 1994

TO: Vivian Gedaly-Duff, DNSc

FROM: Nancy White, Administrative Asst [redacted]
Committee on Human Research [redacted] L-106

SUBJECT: ORS#: 3110
TITLE: Critical Care Nurses' Experiences of Children's Pain.

This confirms receipt of your memo dated March 16, 1994 regarding the amendments to the above-referenced study. You had submitted some revised consent forms, a revised demographic/descriptive questionnaire, and a revised interview guide.

As we discussed during our telephone conversation, this study was reviewed at the meeting on April 8, 1994. The Committee had the following comments:

RECOMMENDATIONS:

The two new consent forms [Acute care: 1) Staff nurse and 2) Parent] were approved as presented. However, if the critical care aspect of the study will continue, the consent forms [Critical care: 1) Staff nurse and 2) Parent] will need to be updated. Marilee Donovan's name should be replaced throughout the consent forms so that these forms are consistent with the acute care forms.

Also, the title for the entire project should reflect the two aspects (acute and critical care). Please provide an updated title.

The study was approved 8-0 with consent form changes and an updated title. Please forward your response to L-106. Highlight the consent form changes to expedite review. Thank you for your cooperation.

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787
Institutional Review Board/Committee on Human Research

DATE: May 10, 1994

TO: Vivian Gedaly-Duff, DNSc SN-FAM

FROM: Nancy White, Administrative Asst[redacted]
Committee on Human Research [redacted]L-106

SUBJECT: ORS#: 3110
TITLE: Acute and Critical Care Nurses' Experiences of Children's Pain.

This confirms receipt of your memo dated May 3, 1994 which responded to the Committee's recommendations for the above-referenced study. The study title was updated to reflect the two phases of the study (critical and acute). All four revised consent forms were reviewed and approved.

Thank you for your cooperation.

OHSU
OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787
Institutional Review Board/Committee on Human Research

DATE: March 12, 1997

TO: Rebecca T. Hill SON-FAM

FROM: Robert D. Koler, M.D.
Chair, Institutional Review Board [redacted]
MacHall 2175, Ext. 4-7887

RE: IRB#: 4417 EX
TITLE: Nurses' Interactions with Families and Children in Pain Care

This confirms receipt of the above mentioned research study proposal. It is our understanding that this study meets the criteria for exemption (Category #4) by the Committee on Human Research. Please see the following excerpt from the Code of Federal Regulations (45 CFR 46.101 b).

Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

This study has been put into our exempt files, and you will receive no further communication from the Committee concerning this study. However, if the involvement of human subjects in this study changes, you must contact the Committee on Human Research to find out whether or not those changes should be reviewed. If possible please notify the Committee when this project has been completed.

Thank you for your cooperation.