Parents' Perceptions of Their Infants' Pain While Hospitalized in Neonatal Intensive Care

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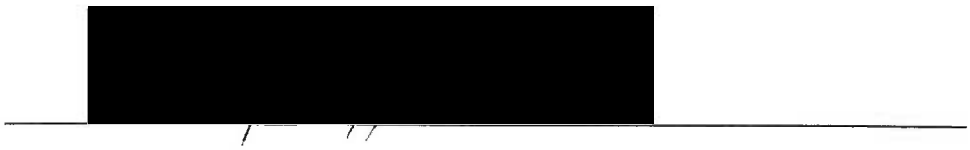

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Abstract

TITLE: Parents' Perceptions of Their Infants' Pain While Hospitalized in Neonatal Intensive Care

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Pain in neonates has been studied since the late 1980's, but there is little information in the literature on parents' experiences with their newborns' pain. This study examined parents' perceptions of the pain experienced by their infant in neonatal intensive care, and their assumptions about pain, and looked at how the infant's pain influenced the infant and the family. The study used a qualitative design based on grounded theory. Open coding, constant comparative analysis, and memo writing ensured adequate representation and generation of pertinent categories. Data were collected from seven sets of parent dyads, who were interviewed two times. The parents entered neonatal intensive care with preconceived notions about pain expression in infants. They used these assumptions to look for the presence of pain in their sick neonates. The parents described pain and non-pain producing events and the signs of pain their infants

displayed. Parents also described behaviors which they attributed to hunger or temperament, but which are recognized in the literature as signs of pain. Families viewed pain globally, not only looking at the present but also projecting into the future. They expressed helplessness, distress, protectiveness, trust, and empathy in describing their experience. This is the first study to report parents' experiences with their infant's pain. In order to provide appropriate interventions, parents' perceptions of infant pain and their reactions to their infants' pain must be clearly identified.

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Chapter 1

INTRODUCTION

Every day, babies endure pain within the first minutes, hours, days, or months of their lives. Technological advances in neonatal care have pushed the frontiers of survivability back to even earlier gestational ages, offering more interventions to infants born too soon and enabling them to survive. However, with these life-saving treatments, infants are exposed to multiple noxious stimuli, and inevitably they experience pain.

The birth of a critically ill infant is the beginning of a stressful period for parents also. Their stress is due in part to problems of the birth and infant's hospitalization in the neonatal intensive care unit (NICU), the infant's appearance and behavior, the environment of the nursery, and alterations in the expected parenting role (Miles, Funk, & Carlson, 1993). The two stressors most frequently cited by mothers of infants are the infant's health status and the infant's appearance, including seeing the infant in pain (Brunssen & Miles, 1996). These stressors for the parents of a sick newborn may affect their ability to adapt their parenting role to their infant's needs and to cope with the hospital environment.

There is, however, little information on how neonatal pain affects families. It is not known what parents observe and interpret as pain in their newborn infants. It is also not known what the impact of neonatal pain is upon the family, and what, if any, meaning that pain has for the establishment of the parenting role.

It is generally agreed that parents have an important role in providing support to their critically ill infants. Indeed, the most powerful influence on an infant's outcome is

support and education of the family (Lott, 1989). Parents who are provided with the information and skills necessary for decision-making about their infant's care are able to provide an environment that facilitates growth and development. NICU nurses, who routinely assess the infant's pain, can teach parents to recognize and understand the pain experience and its impact on the infant, and thus guide parent's interactions with their infants in the NICU. Providing this guidance will encourage parents' participation in caregiving and foster their successful adaptation to parenting an infant with special needs. However, in order to plan appropriate interventions with parents, nurses must understand how parents perceive their infant's pain, how parents react to the experience of the infant's pain, and what meaning the pain has for the family.

The purpose of this study, therefore, was to describe parents' perceptions of the pain, and to examine how the infant's pain affected the infant and the family.

Chapter 2

REVIEW OF THE LITERATURE

The experience of pain is unique to each individual and each occurrence. In adults and children the physiologic process of pain is defined by the individual and then is verbally expressed. In preverbal infants this type of communication cannot occur. The subjectivity of pain and the lack of appropriate tools to measure pain in infants, until recently, resulted in the view that infants do not experience pain and the consequent under-treatment of pain in infants. Indeed, the experience of pain in infants was rarely even discussed until the late 1980's.

The historical view that infants do not feel pain was based on the belief that newborns are neurologically incomplete, lacking the anatomical and functional components for pain experience and interpretation. The immaturity of the fetal nervous system, as symbolized by the lack of myelinization, was thought to inhibit the transmission of pain impulses. It is now known that while myelinization plays a role in impulse conduction, it is not required for pain perception. Although pain impulses are carried more slowly than in the adult, impulses also have a shorter distance to travel in the infant (Anand & Hickey, 1987; Fitzgerald & Anand, 1993); the pathways required for pain perception are present in the neonate.

It was acknowledged as early as 1968 that "myelinization was not necessary for sensory nerve tract functioning" (Swafford & Allan, 1968). Fitzgerald and Gibson (1984), who examined the development of sensory pathways by studying the nervous system of neonatal rats found that while rats and humans have different developmental time tables,

the sequence of developmental events is the same in both species. In the rat, peripheral nociception (both a and c fibers) develops early in fetal life. Neural elements are present at an early developmental age, appearing at 6 to 8 weeks gestation. Later research on nociception and pain impulses carried by myelinated and unmyelinated fibers known as a-delta and c-polymodal fibers led to the conclusion that neonates feel pain and experience pain (Anand & Hickey, 1987; Shapiro, 1989). It was not until 1985, however, when a mother questioned why her infant was not given anesthesia during surgery, that the medical community started asking the same question (Cunningham, 1990). As a result, interest in the treatment of pain began to grow.

According to Anand and Hickey (1987), pain in the fetus and neonate is a result of nociceptive activity producing responses such as crying, increased irritability, wakefulness, distinct facial expressions, prolonged periods of non-rapid-eye movement during sleep, palmar sweating, hormonal and metabolic changes, and increased blood pressure.

After analyzing 3-lead ECG and audio recordings of 20 2-day-old neonates, Owens and Todt (1984), concluded that the neonates reacted consistently following a heel stick with crying and increased heart rate. Similarly, Franck (1986), studied the responses of 10 4-hour-old neonates to acute noxious stimuli using videotaped documentation and observational assessment. Withdrawal of both legs, facial grimacing, crying, and using a "swiping" movement with the unaffected leg were determined to be manifestations of pain following routine heel sticks.

To determine the pattern of infants' pain responses, Johnson and Strada (1986)

analyzed facial expression, cry, body movement, and heart rate during routine immunization of 14 healthy 2-month-old or 4-month-old infants, with normal birth histories. Using the Maximally Discriminative Facial Movement Coding System (MAX) (Izard, 1979), a method of classifying human emotions by observing forehead and brow, eyes, nosebridge, and mouth movements, the authors determined facial expression to be the most consistent indicator of pain in infants.

Grunau and Craig (1987) compared facial expressions and cry across sleep/wake sates following heel sticks, of infants, using the Neonatal Facial Action Coding System (NFACS), to measure expression and digital computer analysis to measure cry. The 140 subjects studied were healthy 2-day-old term infants receiving a routine heel stick. The study showed that neonates in the awake-alert but inactive state responded with the most facial activity to a painful stimulus. During the quiet-sleep state, facial action in response to a painful stimulus was at its lowest and latency to cry was the longest.

Stevens, Johnston, and Horton (1993), studied the responses of 32-34 week gestation infants to acute pain stimuli. The 40 infants were less than 5 days postnatal age and ranged from healthy to severely ill. Facial expression was video taped and coded using the NFACS, infant state was assessed using Prechtl's (1974) Observational Rating scale, and transcutaneous oxygen saturation, heart rate and transfontanelle intracranial pressure were monitored. Heart rate and mean intracranial pressure increased with a decrease in transcutaneous oxygen saturation. Facial expression and cry were similar to healthy full term responses. Sleep/wake state did not influence expression. In addition, severity of illness had no effect on facial action or physiological responses. Cries with a

higher pitch were produced by sicker neonates.

Craig, Whitefield, Grunau, Linton, and Hahjistavropoulos (1993) studied physiologic and behavioral responses to heel sticks of 56 medically stable, 25-41 week gestation neonates. The Neonatal Facial Coding System (Grunau & Craig, 1990) and Infant Body Coding System were used to code behavioral reactions to the painful stimulus. The study found minimal signs of distress in the body and facial activities of 25-27 week gestation neonates. As gestational age increased, the magnitude of response became greater. Increased heart rate, decreased oxygen saturation, and a respiratory pattern characterized by a period of breath holding followed by a period of accelerated breathing comprised the physiologic responses to the heel stick.

Van Cleve, Johnson, Anderson, Hawkins, and Newbold (1995) studied the behavioral and physiologic responses of 30 neonates, with gestational ages of 27-43 weeks and varying degrees of illness and respiratory support, to venipuncture. Data were collected using the Newborn Individualized Developmental Care Assessment Program (NIDCAP) (Als, 1982). Physiologic manifestations of the response to pain included hiccups, gasps, skin color change from pink to red, decreased oxygen saturation, and increased heart rate. Behavioral responses observed were diffuse squirming, legs extended, "sitting on air", flexed arms and legs, hand-to-face motions, and a hyper-alert or cry state.

These studies suggest that infant responses to pain consist of both behavioral cues and physiologic responses. However, it is not known what parents observe and interpret as pain in their infants. Research on parents and their neonates experiencing pain is

lacking, though several studies have described sources of stress for parents of infants in the NICU. Miles (1989), for example, interviewed 53 parents of hospitalized neonates to determine specific environmental stimuli perceived as stressful. The "child's appearance and behavior" and "parental role alteration" were the two areas reported by parents as producing the most stress. The third greatest source of stress reported by parents was observing the "infant acting as if in pain".

In a study by Affonso et al. (1992) of stressors experienced by mothers of preterm neonates hospitalized in an NICU, the mothers reported that the greatest stress resulted from procedures they perceived as painful during the second and third week of their neonate's hospitalization. While these studies looked at pain in the neonate as a source of parental stress, they did not explore how parents determined their infants to be in pain or provide parental descriptions of their infant's pain. Brunssen and Miles (1996), however, studying 57 mothers of medically fragile infants, found that one of the most stressful events for mothers was observing their child experiencing pain. Mothers felt an inability to comfort their child and this was a major stressor. In an earlier study by Eberly, Miles, Carter, Hennessey, and Riddle (1985) 510 parents of pediatric ICU patients also reported that being unable to protect their child from pain was a significant stressor.

Families are concerned with the need to protect and to be "guardians" for their child by responding to health and safety issues (Casteel, 1990). This need to protect from dangers is directly related to the role of parenting an infant in pain. In our society, it is commonly agreed families have responsibility for the health, safety, protection, and general well-being of their children (Jonsen, Seigler, & Winslade, 1992). Parents are

mandated to rear and nurture their infants. The assumption is families will safeguard and meet their infant's needs (Zaner & Bilton, 1991).

However, when families have an infant hospitalized in the NICU, their ability to respond to signs of a threat and to provide the behaviors needed to maintain or improve the infant's status is impaired. As a result families must rely on health care providers to supply them with information about the pain status of their infant, but health care providers often focus simply on the tasks, such as venipunctures and heel sticks for blood work, peripheral IV starts, and dressing changes, needed to improve the infant's survival.

Research has indicated that neonates of similar gestational ages, with varying degrees of illness severity and across sleep/wake states, respond to painful stimuli with predictable behavioral cues and physiologic responses. It has also been suggested that parents define the experience of their neonate's pain as a stressor. However, studies of parents' perceptions of pain in neonates are non-existent. This research was undertaken to develop the nurses' understanding of parents' perceptions of their infants' pain and thus to enhance the provision of care to both the infant and family. Specifically, the study addressed these questions: What are parents' perceptions and descriptions of their infant's pain while hospitalized in the NICU, how do they interpret their infant's pain; and what is the influence of infant pain on the family?

Conceptual Framework

The conceptual framework of the study was G. H. Mead's (1943) theory of symbolic interaction, which places emphasis on the meaning of a situation to the

individual. The meaning of a situation is developed through the interpretation and evaluation of both societal norms and the individual's personal relationships. Behaviors can be comprehended when the individual's perception of the situation are understood. Individuals' perceptions of an event or situation influence their interactions with other people, which in turn influence their parenting and the family system. Parents' definition of pain is formed by the totality of their pain experiences. The parents' response to their infants' pain is shaped by their interpretation of their hospitalized infants' pain experience. When the role of parents is poorly defined, as in the birth of a critically ill neonate, the parents' understanding of the pain experience of their infant may be inaccurate. As a result, they may over or under estimate their infant's pain behaviors, producing an inappropriate parental response. Or, parents may correctly interpret their neonates' behaviors as pain manifestations, but experience difficulty assuming a caretaking role due to the ambiguity of the expectations of parents of a hospitalized neonate.

Chapter 3

METHODS

Design

This study used a descriptive design to examine what parents perceived, understood, and interpreted as pain for their infants. A qualitative approach was used with in depth semi-structured interviews of couples who had infants in a Level III nursery. The qualitative method made it possible to capture accurate and detailed descriptions of a particular point of view (Knafl & Howard, 1984). Grounded theory was utilized to systematically derive the categories that emerged from constantly comparing the analyzed data (Strauss & Corbin, 1990). The purpose of the study was to obtain families' descriptions of their infants' pain and their understanding of that pain.

Setting and Sample

This study was conducted in an 18-bed Level III NICU and a 24-bed Level II intermediate care nursery in a large, metropolitan, Pacific Northwest university medical center. The combined annual admission rate for the units is 650 neonates.

Study subjects were coupled parents of hospitalized neonates. The couples were not first-time parents; were fluent in English; had infants who were not unduly unstable; were members of any cultural and/or racial origin; and were not unusually upset at the time of the interview, as determined by the judgement of the interviewer. During a 9-month period, 21 couples were eligible for the study and 7 couples volunteered to participate. Both parents were interviewed together.

The parent couples were biological mother/father relationships exclusively. Parent

ages ranged from 18-41 years (M = 31). Four couples were married and three were partnered. The number of other children living at home ranged from 1-7 (M = 2.3). Most parents were Caucasian 13, but 1 was Hispanic. Formal education ranged from completion of the 11th grade of high school to a master's degree. Occupations ranged from none to middle school teacher (see Table 1).

Table 1

PARENT DEMOGRAPHICS

FAMILY	AGES & GENDER	MARITAL STATUS	NUMBER OF SIBLINGS	ETHNICITY	EDUCATION	OCCUPATION	RELIGION	LOCATION OF RESIDENCE
A	41M 21F	partnered	4	Caucasian same	3 yrs college 1 yr college	self-employed homemaker	none Christian	outside metro area
B	32M 27F	married	1	Caucasian same	2 yrs college completed high school	autobody repair homemaker	none Christian	outside metro area
C	36M 33F	married	7	Caucasian same	high school completed, same	self-employed logger, homemaker	Christian same	outside state
D	20M 18F	partnered	1	Caucasian Hispanic	high school completed, same	lift operator none	none Christian	outside metro area
E	35M 27F	partnered	1	Caucasian same	2 yrs college 11th grade	none none	Christian same	outside metro area
F	36M 36F	married	1	Caucasian same	4 yrs college Masters degree	banker middle school teacher	none Christian	outside metro area
G	35M 36F	married	1	Caucasian same	high school completed, 2 yrs college	warehouse foreman, hairdresser	Christian same	outside metro area

The parents were predominantly Christian (n = 11) with three reporting no religion. The infants were all singletons; 5 were females and 2 were males. Gestational age at birth ranged from 25 weeks (preterm) to 40 weeks (term). Three infants were term, aged 38 weeks or older, 2 neonates were preterm, aged 33 to 36 weeks; and 1 was an extremely low birth weight infant, born at 25 weeks gestation. Infants' ages at the time of the interview ranged from 4-25 days (M = 14 days). Medical diagnoses were in 3 groups; 3 infants were premature, 3 infants required surgical repairs, and 1 infant was premature and required surgery (see Table 2).

Table 2
INFANT DEMOGRAPHICS

Infant	Gestational Age	Diagnosis	Age at Interview	Medical History	Status at Interview
A	38 weeks	cystadenomatoid formation in left lower lobe of lung requiring surgery	10 days	ventilator, surgery x 2 days, central and peripheral intravenous fluids (IVFs) 2 chest tubes, Fentanyl drip, Tylenol, antibiotics	nipple feedings, crib, discharge within 24 hours
B	39 weeks	pulmonary sequestration requiring surgical repair	4 days	ventilator, lobectomy, peripheral IVFs, oxygen via nasal cannula, 1 chest tube, Morphine, Tylenol, antibiotics	breastfeeding PRN Tylenol, crib, discharge within 24 hours
C	25 weeks	prematurity, extremely low birthweight	21 days	ventilator, phototherapy, central and peripheral IVFs, blood product transfusions, dopamine, dobutamine, insulin, surfactant, pentobarbitol, Valium, Fentanyl, antibiotics, Indocin, hyper-alimentation, lipids, jejunal drip feedings	high frequency ventilation, central IVFs
D	33 weeks	prematurity	4 days	peripheral IVF, phototherapy, antibiotics, PRN gavage feedings	PRN gavage feedings, breast-feeding, crib
E	40 weeks	gastroschisis requiring surgical repair	25 days	ventilator, surgical repair x 2, gastrostomy, central and peripheral IVFs, blood product transfusions, antibiotics, Fentanyl drip, Tylenol	
F	36 weeks	prematurity	8 days	nasal continuous positive airway pressure, oxygen via nasal cannula, central and peripheral IVFs, phototherapy, antibiotics	breastfeeding, crib, discharge within 24 hrs.
G	35 weeks	prematurity, Downs Syndrome, duodenal atresia requiring surgical repair	23 days	ventilator, surgical repair x 2, gastrostomy tube, central and peripheral IVFs, Fentanyl drip, Tylenol, antibiotics	continuous drip feedings, crib

Data Collection

Demographic Questionnaire

Demographic data was collected on the mother and father of the hospitalized infant and on the infant. Parents of the infant filled out the demographic questionnaire either the day before or the day of the interview. The couple data gathered included name, gender, age, marital status, education, occupation, religious preference, ethnic background, and relationship to the infant. The infant demographics included gestational age at birth, diagnosis, length of stay at time of interview, APGAR, and gender (see Appendix B).

Interview Guide

The investigators developed a two-part interview guide (see Appendix C). Part One comprised questions asking about the infant's pain in the neonatal intensive care unit. Specifically, parents were asked to describe an incident when they thought their baby was in pain; what their baby did that made them feel he/she was in pain; what things they felt caused their baby to be in pain; what were some of the things their baby did to let them know he/she was in pain; what they thought made their baby's pain go away; what they did when they felt their baby was in pain; and who helped them know their baby? All first part interviews were conducted on the unit, away from the infant's bedside, in the family room. One of the investigators would conduct the interview. Of the seven interviews, one investigator conducted four interviews, one investigator conducted two interviews, and one investigator conducted one interview.

Part Two, which was conducted at the bedside of their infant, consisted of open-

ended questions about how they thought their infants looked, how they interpreted their infant's appearance, whether anything made them concerned for their infant's comfort, and any other feelings and thoughts they had at that time. When parents found it difficult to answer an interview question, the interviewer attempted to gain further clarification with the use of probes such as "What would you see if your baby was in pain?" or "What things would you expect to cause your baby pain?"

Procedures and Protection of Human Subjects

Couples were informed of the study and its purpose by the investigators. When they agreed to participate, they were asked to sign an informed consent that was approved by the Oregon Health Sciences University Institutional Review Board (IRB), Committee on Human Research (see Appendices D & E). The investigators conducted the interviews and couples who participated were assured that all data would be kept locked, without identifying features. Following data collection, there was time for an opportunity to share any concerns that might have arisen during the interviews.

The IRB for Oregon Health Sciences University (OHSU) reviewed the study. When families were identified as eligible for study participation, they were contacted by one of the investigators and invited to become part of the study. The study was explained to the family and questions about it were encouraged. When it was determined that the family was willing to participate, an informed consent form that covered liability and questions was presented to potential participants. The subjects then read and signed the consent form. The purpose of the study was to describe parents' understanding of their infants' pain. The risks to families included psychological discomfort in discussing their

infants' pain. Parents were told if an investigator sensed any anxiety during the interview, the interview would be discontinued and the couples would be encouraged to speak about their discomfort. However, no families voiced any concerns during the interviews. Subjects did not receive any benefit from this study other than being able to tell their story about their infants' pain and its meaning to them. The couples, however, said it gave them positive feelings to have a place to speak about this subject. All subjects were assured that they could withdraw from this study at any time and all data would be destroyed that day. It was emphasized that in no way would their decision damage their relationship with OHSU. No subjects wished to withdraw from participating in this study.

Subjects were asked if they could be audio tape recorded during the interview and none declined. The audio-tapes were destroyed after the completion of the study. Subject data were kept confidential by maintaining locked files of the data collection materials. Consent forms were kept separate from the descriptive and questionnaire data. A coding system was used to track units of data and names. Other identifying information was not connected with the data. Only the investigators had access to the data and the coding key that connected names with data was stored separately in a locked file and destroyed at the conclusion of the study.

Data Analysis

The interviews were transcribed verbatim. Analysis involved reading and re-reading each interview to identify themes, commonalities, and differences in the participants' understanding of their infant's pain. The investigators read the interviews separately and met to discuss the selection of categories and codes until consensus was

reached on the most salient ones. Once codes and categories were identified and agreed upon, the investigators re-coded the previous interviews. As the interviews progressed, they were read and coded separately by the team members. Interrater reliability was calculated and major discrepancies were discussed in order to achieve interrater reliability of at least 95%. As the interviews were coded, the ETHNOGRAPH software program was used to enter codes and categories and to sort the data for retrieval for ensuing analyses (Seidel, Kjolseth, & Seymour, 1988).

In the second stage of analysis, excerpts for each category were looked at for common recurring categories. Memos were written to capture the investigators' understanding of the properties and dimensions of each category (Strauss & Corbin, 1990). Sampling continued until the categories were saturated. No new categories emerged with the seventh interview and data collection was therefore concluded.

Chapter 4

RESULTS AND DISCUSSION

Analysis of the data brought forth two categories describing parents' perceptions of their infant's pain. The first category, parents' perceptions, consisted of four properties: parents' preconceptions of infant pain, parents' perceptions of infant pain, parents' perceptions of non-pain, and parents' perceptions of other behaviors. Parents' perceptions of infant pain is comprised of the dimensions of signs of infant pain, sources of infant pain, magnitude of infant pain, and treatment of infant pain. The second category, parents' responses to infant pain, consisted of the properties of helplessness, distress, protectiveness, trust, and empathy.

Parents' Perceptions

Most of the situations individuals experience in life are framed by their previous experiences with similar situations. An individual draws on these past experiences to provide an initial meaning for a new experience and potential responses to the situation. For most individuals, being the parent of a hospitalized newborn is a novel situation during which they are calling upon their interpretations of previous experiences to provide structure and meaning to a new situation. This presentation of parents' perceptions begins, therefore, with the preconceptions of infant that parents had formulated prior to the birth of their infant.

Parents' Preconceptions of Infant Pain

When they enter the NICU, for the first time, experienced parents bring with them a wide range of information about the phenomenon of pain. Parents have acquired ideas

about pain through their experiences and those of their children in pain producing incidents. These experiences form their preconceptions of pain. Parents draw on these ideas to give meaning and context to novel situations. When in the unfamiliar and novel environment of the NICU, the parents in this study relied on their preconceptions of pain to interpret their infant's behaviors. The parents' knowledge of infant pain was based on their preconceived notions that certain situations, such as falls and bumps, produce pain, and specific behavioral responses, such as crying, facial expressions, and body movements, indicate pain resulting from physical injury. The parents anticipated pain in their infant following surgeries and procedures that caused tissue damage.

They assumed their infants would have pain following surgery, from chest tubes, and from wound infections. One father (Family A) described his term 10-day-old daughter's situation after surgery as: "But you knew that she was in pain, or I did, just because of the studying I had done." This father's assumption of pain in his daughter came from extensive preparatory self-education in anticipation of the surgery for his daughter's diaphragmatic hernia.

The parents of a 4-day-old term infant (Family B) expected their son to have pain following thoracic surgery accompanied with a chest tube. When asked to describe a situation when their infant was in pain the mother said: "I don't think he was really in pain, he didn't show any signs of it."

The father said: "But that's where we figured he would be in pain...I was concerned about the tube [chest tube]."

The mother continued: "'Cause it was a larger tube than they normally use."

The mother said: "Wrinkle his brows."

The father continued "Cry."

The mother added: "Scrunch up his legs."

Another set of parents (Family C) of a premature described similar behavioral signs. The father said: "She would cry."

The mother added: "She would wince. She would wrinkle up her eyebrows."

The father continued: "She'd do that and move her legs back and forth."

The behavioral responses of crying, wrinkling the face and eyebrows, wincing, and moving the arms and legs described by parents correspond to those reported in the literature (Anand & Hickey, 1987; Franck, 1986; Grunau & Craig, 1987, 1990; Johnson & Strada, 1986; Stevens, Johnston & Horton, 1993). Healthy term infants vividly display pain behaviors making their interpretation easy for parents. However, the pain displays of an extremely ill or premature infant are diminished in magnitude because of the infant's low energy levels (Craig et al., 1993). These parents who had 1 to 7 children at home, were experienced parents. They were familiar with the pain responses of healthy term infants, but they could not identify the muted or altered responses of their ill or premature infant as pain behaviors.

Parents also thought that their infants might not have the capacity to experience pain in the same manner as an adult. The mother of a 3-week-old neonate (Family C) born at 25 weeks gestation described her preconceptions of her daughter's pain experiences. She said:

I think that her body can feel pain, but it doesn't go to her head, you know what I

> mean? What I'm trying to say is that she's really underdeveloped. Her organs, lungs, brain, smell, sight, hearing aren't mature. I don't think she feels things the same as we do. Anyway, I hope she doesn't. I know she won't remember any of this. Not like I remember the c-section and waking up at night to re-experience parts of it. She's just too underdeveloped, I think it's more discomfort than pain.

This mother had vivid memories of the birth of her daughter, the emergency cesarean-section, and her emotions about the birth. She thought her daughter did not have the capacity to experience pain because the infant was born prematurely. She assumed the infant did not have the capacity for memory, emotions, or mature organ functioning. However, this is not what neurophysiologists (Anand & Hickey, 1987) have discovered and is not what parents are told by the nursing and medical staff.

In this study, parents brought with them the expectation that their infant would experience pain while hospitalized. They based their interpretations of their ill infants behaviors on their own pain responses and the responses of their other children when they were infants experiencing acute pain. Parents expected their infants to cry, wrinkle their face and eyebrows, and move their legs to indicate that they were in pain. The parents expected situations such as surgery, chest tubes, and wound infections, to produce pain. However, parents assumed that premature infants could not experience pain in the same manner as adults. With the knowledge that parents have preconceptions about the pain in infants, the nurse can assess their assumptions and inform the parents of the many causes of pain in hospitalized neonates, the wide range of behavioral responses to pain, and the specific needs of their infant. This will do much to improve the parent/infant relationship and bring the family into the infant's life.

Parents' Perceptions of Infant Pain

Parents brought with them to the NICU some understanding about what pain in their infant was and was not. They watched for specific behavioral pain signs, such as crying, facial expressions (grimacing, frowning), and body movements (clenching, twitching). Four main dimensions of what parents perceived as infant pain were discovered: signs, sources, magnitude, and treatment of pain. This section describes parents' perceptions of these dimensions and discusses the implications of their meaning for the infant hospitalized in the NICU.

Signs of Infant Pain

Parents identified crying, facial expressions, and body movements as signs of pain in their infants. All three of these behaviors are also documented as signs of pain in infants in the literature (Anand & Hickey, 1987, 1993; Franck, 1986; Fuller & Conner, 1996; Fuller, Thompson, Conner & Scanlan, 1996; Grunau & Craig, 1987, 1990; Izard, 1979; Johnston & Strada, 1986; Owens & Todt, 1984; Prechtl, 1974; Stevens, et al., 1993; Van Cleve, et al., 1995).

Crying. Crying was identified by all parents as a sign of pain. A mother of a 25-day-old term infant (Family E) who was born with an unsuspected abdominal wall defect that had required two surgeries to correct was asked what her daughter did to let her know she was hurting. She said:

> Y-y-you just see it when she's awake, her eyes are red and she cries when she's awake. With a tube down her throat you can't hear her cry but you can see her cry. I think that's worse than not even hearing it. Her eyes are all swollen and red. She just she hurts. It's hard.

Crying, whether verbal or silent, was recognized by all these parents as a universal response to painful stimuli and their infant's way of communicating to the parents that the infant was in distress. Not all infants were able to verbalize cries because of mechanical ventilation or a lack of physical energy. Nevertheless, parents recognized their infants' crying as a signal that their infant was in need. Crying has been identified as a consistent reaction to painful stimuli in term infants. (Grunau & Craig, 1987; Owens & Todt, 1984). Thirty-two to 34 week gestational age preterm infants have been shown to have responses to pain that are similar to healthy term infants, though these smaller infants respond with shorter and higher pitched cries (Stevens & Franck, 1995; Stevens, et al., 1993).

Facial Expressions. Facial expressions were frequently described by the parents as a sign that their infants were experiencing pain. Parents watched for bunched up faces (grimacing), frowning or wrinkling, and flinching as indicators of pain. One family, whose 10-day-old 38 week gestational age infant (Family A) was born with a suspected diaphragmatic hernia, described their daughter's face and body flinches after surgery. When asked if there was one incident that really showed them their daughter was in pain, the mother answered: "When she got her respirator out and she couldn't barely swallow or cry or anything and that was, her throat."

The father then said:

> Well there was a lot of times that you could see her in pain, when the medication was - when they'd lighten up on it, you know, you could tell. Then they would increase the dose because of the faces and flinches.

The mother added: "Makes faces and stuff. She'd bunch up."

Change in facial expression has been determined to be the most consistent indicator of pain (Johnson & Strada, 1986; Stevens & Franck, 1995). Neonates in the awake-alert but inactive state have been found to respond to painful stimuli with the most facial activity (Grunau & Craig, 1990). Furthermore, term neonates have been found to consistently respond to painful stimuli with five parameters of facial expression: brow contraction, eye squeeze, naso-labial furrow, open mouth, and taut tongue.

Severity of illness had no effect on facial activity in studies of 32 to 34 week gestational age preterm infants (Stevens et al., 1993). However, medically stable 25 to 27 week gestational age preterm infants responded to painful stimuli with minimal signs of facial activity. As gestational age increased, the magnitude of the responses became greater (Craig, et al., 1993).

The parents in this study did not differentiate between term and preterm facial activity in their infants in pain. They all recognized the facial expressions of grimacing, bunching or wrinkling as signs of pain in their infants. Although preterm infants, because of low muscle strength and energy, may be unable to display as vigorous pain cues as their term counterparts, the parents interviewed did not recognize these differences in their infants. None of the parents in this study had had previous experience with a preterm infant, and thus they had not had any opportunities to learn about specific preterm infant behaviors.

Body Movements. Body movements, such as flexing of arms and/or legs, were described by parents as indicators that their infants were in pain. Parents described fist clenching, legs drawn up tightly and twitching movements as signs of pain in their

infants. When the family of the 10-day-old 38 week gestational age daughter (Family A) born with a suspected diaphragmatic hernia were asked what facial expressions made them feel that their daughter was comfortable following her surgery, the father said "Well, she's alert, there's no cringing, she's looking around, not as before you know, she was always clenched."

When asked what clenched meant, the father said: "Fist drawn and her face wrinkled and uptight."

The mother then added: "Her legs drawn up. Her legs drawn up to her chin."

These parents were able to recognize and interpret their infants' body movements as responses to painful stimuli. The movements they identified as indicative of pain have also been cited in the literature. Researchers have found that vigorous withdrawal of both legs and "swiping" movements of the unaffected leg were common pain responses of healthy term infants to heelsticks (Franck, 1986). However, critically ill or preterm infants were found to respond to noxious stimuli by becoming limp or flaccid (Franck, 1993). One study found minimal behavioral response to heelsticks in preterm infants, with only withdrawal of the affected leg and no cry or grimace (Rich, Marshall, & Volpe, 1974). Neonates from 27 to 43 weeks gestational age responded to venipuncture with diffuse squirming, flexed arms and legs, extended legs, and hand-to-face motions (Van Cleve et al., 1995).

The parents in this study did not note the decreased muscle tone or movements of preterm infants discussed in the literature. Again, since these parents were inexperienced with preterm infant behaviors and new to the NICU environment, these more subtle pain

behaviors might have gone unnoticed or been misinterpreted by parents as non-pain.

Sources of Infant Pain.

Sources of infant pain identified by the parents included being intubated, chest tubes, surgery, and procedures such as Pic-line (Percutaneous line) placement, heelsticks, and gavage feedings. When the family of the 10-day-old 38 week gestational age daughter (Family A) born with a suspected diaphragmatic hernia were asked "What were some of the things that you feel caused her pain?" the father replied: "Surgery."

The mother then added: "Her chest tubes, that definitely hurt."

This family assumed that their daughter's surgery and accompanying chest tubes and intubation were painful and they watched their daughter to make sure she was as comfortable as she could be. The father went on to talk more about his daughter's pain: "But you knew she was in pain, or I did, just because of what, again, the studying I had done. If it wasn't for the drugs, she would have been in pain." This father recognized the importance of pain medication in his daughter's recovery from surgery. He was aware of his daughter's needs based on what he had learned in the preparation for the birth of his daughter.

Another family whose 21-day-old daughter was born at 25 weeks gestational age (Family C) described their daughter's experience during a medical procedure. When asked to focus on a time when the parents felt that their daughter was in pain, the mother replied: "Well, I really don't know. I really couldn't say of a time. She did do some twitching in her legs after they put in a pic-line." Describing the procedure in more detail, the mother went on to say:

> She was covered with cloths. I saw her skin being cut on her leg and she didn't move that I could see. Then I left because they said I probably didn't want to watch the rest. Anyway, when they finished, I came back and that's when her leg began to twitch. Her nurse said she would sedate her because she might be hurting, but then it stopped.

This mother was describing a percutaneous catheter cutdown procedure that her daughter underwent twice (the first attempt was unsuccessful). Even though her daughter had been given a local anesthetic, this mother knew her baby's behavioral cue was a sign that she was in pain. She knew how her daughter was feeling during the procedure and was interpreting her leg twitch as pain. The nurse validated the mother's interpretation of her infant's behavior.

The father of an 8-day-old son was born at 36 weeks gestational age (Family F) with respiratory distress from hyaline membrane disease said:

> I guess the biggest example that when they were drawing blood out of his heel it looked like they were having to squeeze his foot fairly hard. And so even as they release his foot it was still all mashed in and white in color and it didn't really look like a foot, you know, and so...

This father watched his son having his blood drawn from a heelstick, a routine nursing procedure that his son underwent many times while he was having difficulties breathing. This father described how the heelstick affected his son:

> He was - he gets pretty - yeah he gets pretty worked up about it - crying and trying to scream as much as he could. He was on a real - he wasn't really screaming a whole lot because I think he was still struggling with his breathing pattern.

This father recognized that his son was in pain by the behavioral cues he was displaying. He also recognized that his son's illness was secondary to immaturity, and assumed that his son was unable to cry as much as he might have, had he been more mature.

Magnitude of Infant Pain

The parents in this study viewed pain along a continuum, from major to minor. They used the magnitude and intensity of pain to differentiate the types of pain that their infants were experiencing. For example, the father of the 10-day-old 38 week gestational age daughter (Family A) said: "And then having two surgeries where she should have had only one. That compounded the, I'm sure, the pain." This father was referring to his daughter's surgery for a suspected diaphragmatic hernia (diagnosed prenatally) that was, in fact, not a diaphragmatic hernia. During surgery, the surgeons found a cystadenomatoid malformation, requiring a different type of surgical repair. The father described what happened next:

> She went down. They misdiagnosed it. So she went down for the diaphragmatic hernia. And they did the incision and found out that wasn't the fact. And then they came up and located us, kept her sedated and then came up and located us for another consent, and then opened up the chest cavity and the cyst.

This father interpreted his daughter's experience as more painful since she had to experience *two* surgeries and had *two* big incisions as a result. His perception of his daughter's pain seemed to be magnified by the size of her incisions. He was vigilant in his monitoring of his daughter's recovery and her pain and medication needs.

This father's perceptions are consistent with what is found in the literature. The energy required to maintain heart rate, blood pressure, and oxygenation during pain depletes resources that would otherwise be used for tissue growth and repair. Prolonged pain depletes an infant's stress hormones. The use of anesthesia during and analgesia following superficial, intra-abdominal, and intra-thoracic surgery in term infants has been

found to decrease infants' stress responses (Anand, 1993).

In discussing the intensity of pain, parents' described their infants' pain as minor or major and distinguished discomfort from pain. The mother of the 21-day-old 25 week gestational age infant (Family C) said she felt that her daughter sometimes experienced discomfort rather than pain. When asked to describe discomfort vs. pain, the mother said:

> Well, there's a big difference. It's like when one of M's brothers or sisters falls down and bangs themselves. The bumping really hurts and they cry from it. But in a couple of minutes they're over it. The scrape or bruise is uncomfortable because it's sore.

The father clarified: "Yes, pain is a much stronger feeling, discomfort is an irritating thing that you can forget about most of the time."

Then the mother added:

> We know she may be uncomfortable, but we don't want to dwell on it because she won't hurt for long and then it's all over. She has to endure this to survive. It's mind over matter. I do feel her pain.

This family differentiated between their daughter's feelings of pain and feelings of discomfort, using their older children's behaviors and experiences as a guide. However, the assessment of pain in preterm infants is more difficult than in term neonates and older infants because behavioral responses of the preterm infant to pain, can be more variable and less vigorous (Stevens & Franck, 1995). Research has shown that a lack of response to painful stimuli in the preterm infant does not necessarily indicate an absence of pain. A lack of response in stressed and immature infants may actually indicate a depletion of energy reserves and of capacity for response (Franck, 1993). Thus, parents of preterm infants, unless taught about their infant's specific behaviors, may be unable to

accurately interpret their infants' pain cues.

Treatment of Infant Pain

Parents expected pain relief for their infants by the use of medications and comfort measures as gentle handling. They watched their infants' behaviors for signs of pain relief and comfort and an absence of pain behaviors. They described the behaviors that helped them identify when their infant was comfortable and pain-free. The father of the 10-day-old 38 week gestational age daughter (Family A) who experienced two surgeries said:

> Well there was a lot of times that you could see her in pain, when the medication was - when they'd lighten up on it, you know, you could tell. Then they would have to increase the dose because of the faces and flinches.

Another father of a 21-day-old 25 week gestational age daughter (Family C) described what he felt his daughter's pain medication experience had been: "I think they give her enough anesthesia to keep her comfortable when she needs it." Both fathers watched their infants behavioral cues for signs of pain relief, were aware of their infants' needs for pain medications, and were similar in their assessments.

Gentle handling was also identified as a form of pain treatment by parents. They watched their infant's behavioral cues for signs of pain or discomfort and then handled them accordingly. The mother of a 4-day-old term infant (Family B) who had had surgery for a pulmonary sequestration, which necessitated placement of a chest tube, described how she handled her son during breast feeding: "I don't pick him up like that, I pick him up like this and then my concern is burping him." This mother had learned how the infant was most comfortable and helped him with her handling. She supported him with a

pillow on her lap, and moved him slowly and gently, aware of the position and movement of his chest tubes. This was a form of pain treatment. Non-pharmacological "comfort" measures have also been cited in the literature as a means of pain management for infants in the NICU. Gentle handling, gentle manipulation of tubes, and positioning have been found to support an infant's own coping mechanisms, thereby helping the infant to recover from painful stimuli (Franck, 1993; Stevens & Franck, 1995).

Parents' Perceptions of Non-Pain

In much the same way that they looked for signs of pain, parents also monitored their infants for signs of comfort. The family of the 10-day-old 38 week gestational age suspected diaphragmatic hernia infant (Family A) described what non-pain in their daughter was to them. The mother said: "She just slept for a very long time."

The father added: "Yeah, real peaceful and not a lot of movement and...." When asked what made him feel his baby was peaceful, the father said: "Just because of her sleeping. Being asleep and not moving around or thrashing around or anything like that." Based on previous experiences, the parents looked for happy, sleeping, peaceful infants without painful expressions or behaviors.

Another family (Family C) who were at the bedside of their 21-day-old 25 week gestational age daughter, described what they saw this way. The mother said: "She feels happy. Her eyes are closed. She's sleeping."

The father added: "Her arms and legs aren't moving." When asked what their daughter was doing that made them think she was not in pain, the mother answered: "Her hands, they're not tight, they're relaxed, her arms and legs are up against her and relaxed,

too. She looks like she's very comfortable." The father added: "She looks like she is sleeping peacefully."

Finally, the family of an 8-day-old 36 week gestational age infant (Family F) with hyaline membrane disease described what non-pain was to their son. The mother said:

> He looks just - he looks like a regular baby now. I mean he's just, you know, he's sleeping. He sleeps comfortably and I think - I mean he's just doing the things that our other baby did, you know, I mean. You know, he grabs with his hands, and he, you know, looks at us when he's awake and when he's sleeping - he's just - and it's nice to see his chest not heaving. You know, he just looks real peaceful and content little baby. It makes me feel good to know he's going to come home soon.

To which the father added: "He looks a lot better than he did a week ago."

Parents described watching for signs of pain, pain relief, and comfort in their infants. Although faced with unexpected illness in an unfamiliar environment, they were able to use their previous experiences as parents to get to know their new baby and to assess the behaviors of their sick neonates.

Other Behaviors

Parents observed their infants exhibiting many behaviors in response to the care they received. The parents interpreted these behaviors as being tired, mad, hungry, groggy, or dreaming. For example, a mother and father of a 4-day-old term infant (Family B) described his first attempt to breastfeed 36 hours after a lung lobectomy. The mother said:

> When I came in we [mother and infant] tried to nurse, I don't know if he was still pretty tired, kind of groggy, but he got mad, we [mother and nurse] had him laying on his side. I don't know if it was kind of uncomfortable or if he was just mad about it, or didn't want to nurse in that position because of the scar.

The father added: "I think he was more mad about trying to nurse."

The mother continued: "I think he just wanted to be in one position and have somebody hold the bottle and let it be easy."

The father continued: "Because he'd lock up his lips."

These parents went on to describe difficulties interpreting their son's unfamiliar cues. The father said: "But he never really, I really don't know that he's showing pain."

The mother added: "He kind of, his face all tightened up and his body, he turns red, you can tell he's either mad or in pain, one of the two, I don't know - or both." These parents were not sure how to interpret their infant's behaviors. Similarly, the parents of a 3-week-old 25 week gestation infant (Family C) related their uncertainty interpreting their daughter's behavioral cues.

The father said:

> I did see her doing something though that I think was [pain] because she was very uncomfortable from the high pressure they needed for the ventilator to work for her. She was laying on her back with her legs tucked up, with blankets holding her feet up. And she would press her feet down and arch backwards...

The mother interjected: "She would lift her back completely off the bed, with at least an inch between her and the bed. I was amazed a tiny thing like her having the strength to do that." These parents attempted to interpret their infant's behaviors and to give meaning to their observations. However, both sets of parents lived at least an hour's drive from the hospital and may not have been able to spend enough time with their ill newborns to learn to interpret their nonverbal cues.

There is no question that their infants were exhibiting signs of discomfort of

distress. This emphasizes the importance of educating parents that ill infants and preterm infants may display unfamiliar behaviors in response to pain. Parents do not have refined knowledge of the medical/nursing environment and are unfamiliar with factors that can contribute to their infant's pain. Parents must be encouraged to look at not only their infants' actions but also influences from the infants' environment, such a noise and light levels and sudden changes in ambient temperature; number of post operative days; poor analgesia overage; presence of a respirator; over handling; and not being held or soothed, all of which can influence an infant's response to pain.

Parent Responses to Infant Pain

Parent responses to their infant's pain rested on their understanding of parenting generally and the particular meanings of being a parent of an infant experiencing pain in a NICU. Society and families see parenting as a moral responsibility to protect, nurture, safeguard, and take care of their children (Stark & Thape, 1995). Miles and her colleagues (1992) documented that the NICU altered the parenting role and created stress for parents. The study reported here, not only found that parents were stressed, but their stress was intensified when events did not go as planned and their infants experienced painful situations. These parents talked both about physical pain for their babies and the emotional pain of being a parent with a child in a NICU. In the process of being with their children in the NICU, these families experienced hopelessness, distress, protectiveness, trust, and empathy for their infants.

Helplessness

Helplessness was the most frequent emotion voiced by parents. Families

described feeling helpless when they could not stop their infant's pain; when they could not 'be there' for their infant and had to rely on others; and when they feared for the life of their child.

Inability to Stop the Infant's Pain

One of the worst things parents described was seeing their child in pain and being unable to do anything about it. When asked, "What was it like for you the first time you saw your daughter in the neonatal intensive care unit (NICU)?" The father of a baby girl who was born at term and had two surgeries before admission to the NICU (Family A) said: "Yeah, it was just overwhelming seeing a little newborn like that, in pain and on a respirator."

A mother of a preterm infant described what it was like for her to sit at her daughter's bedside, helpless to do anything for her. She said: "Because you can look at her and just tell she hurts and there is nothing you can do."

The family (Family E) that experienced multiple surgeries for their daughter who was diagnosed with gastroschisis talked about their helplessness. The mother said:

> Especially when she's like she is now (on a respirator and very pale) because you can look at her and just tell she hurts and there is nothing you can do. Y-y-you just see it when she's awake, her eyes are red and she cries when she's awake. With a tube down her throat you can't hear her cry, but you can see her cry. I think that's worse than not even hearing it. Her eyes are all swollen and red. She just, she hurts. It's hard...[I feel] helpless, helpless.

The father continued:

> ...just looking at her like she's in pain - like grabbing [mom's] finger and just not wanting to let go. And then know that - well for me - knowing that I can't do a thing to make the pain go away. That pretty much makes me mad. I feel like I'm the father and I'm supposed to, you know, take the pain away.

These families observed their babies in pain and felt helpless to stop it. Families are expected to protect their infants from harm and create a safe, secure environment for growth. In the environment of the NICU, families are unable to perform these societal and parenting roles. This magnifies the helplessness families experienced.

Not Being There and Relying on Others

Two families whose children had surgery described the helplessness of sending their children off to surgery and relying on someone else. One father, whose son had thoracic surgery for a pulmonary sequestration (Family B), described feeling helpless because he was unable to do anything for his child. He said:

> The worst feeling was, was the not knowing about how he was going to go through surgery. The complete helplessness. You know you don't - you feel helpless, you cant do anything and you're not going to be able to be there [in surgery] to see what's going on.

Another father acknowledged the same feeling of helplessness.

> Sort of helplessness because you know you can't do anything. And you're relying on what you're being told by the nurses and doctors and you don't know if you're always being told everything.

Besides feeling helpless because they were unable to do anything for their child; these fathers felt helpless at placing their child in other people's care. This is consistent with studies by Casteel (1990), Levey-Schifee, Hoffman, Mogilner, Leveringer, and Mogilner (1990), and Miles et al., (1993) in which helplessness was identified by parents as one of the major stressors of having a baby in the NICU. In the environment of the NICU, families are unable to perform their societal and parenting roles as they know it, which can magnify their feeling of helplessness. Having to rely on others to care for and

relieve their infants' pain, parents suffer emotionally because of their feelings of dependence and helplessness.

In this study families said that placing their baby in someone else's care, when normally they would be home caring for their child, produced intense feelings of helplessness. Their baby was now very ill, which challenged their ability and confidence.

Fear for the Infant's Life

Families additionally reported feeling fear that their child might die. They feared that through all the pain their child experienced, their child still might not survive. A mother of a baby girl born at 35 weeks gestation, who was diagnosed with duodenal atresia and trisomy 21 (Family G), spoke of this fear:

> I just don't think you can take it all in (the baby's pain, the NICU, being a parent) the first time, you know, and when you're, you know, your child is in such a critical state that you're just concerned about whether or not she's going to be here the next day at that point.

Similarly, Miles and her colleagues (1992, 1993) found that parents with infants in the NICU voiced these same feelings of fear. Parents feared that their baby would not survive and they felt helpless to save their child.

Distress

In addition to helplessness, parents identified concerns, anger, and distress linked to the times when they felt their infants were encountering pain and they could not prevent, help, or stop their infant's pain. Their distress was particularly great in response to the prolonged pain of their infant, and pain during care-giving activities such as turning and feeding.

Prolonged Pain

One father described how he felt about a delay in removal of the chest tube in his daughter (Family A). When the surgeons failed to remove the chest tube on the day the father was told it would be removed, he felt his daughter had experienced prolonged pain. He said:

> And the only [thing] that I am annoyed about, this whole thing on this pain deal is the chest tube stayed in a day longer because the surgeons failed to get up here to take it out. And I know that was creating pain...that day was unnecessary in [her] short life span. Well, I mean, I'm not saying the surgeons didn't do a good job, they done a great job. But that day was unnecessary in [a] short life span. She's [gone] so far to be in pain [any longer], and I don't like drugs, so that meant she was on drugs longer because of the pain.

This father was gently holding his daughter as he described this experience. He placed the event in the context of his daughter's short life and the understanding of all the pain she had already endured. Families want health care givers to cherish their children as they do. The delayed removal of the chest tube for this child showed little concern for the infant's comfort.

Pain During Care Giving

Parents voiced concern for their child as they tried to meet everyday needs, such as holding and feeding their baby. A father whose child had had surgery for a pulmonary sequestration talked about his concerns when the mother was trying to breastfeed their son (Family B): "We were concerned about his cut [surgical incision site]." The mother echoed the father's feelings: "I was concerned about it. Where his chest tube was from surgery, where his scar was..."

Another family identified 'gavage feeding' as a painful event for their daughter.

When the mother was unable to hold her premature daughter during her daughter's gavage feeding, she said: "I don't know, seeing it [gavage feeding] was just like - made me really upset because usually when they gavage her...I'm holding her."

The father continued and voiced his anger at the situation. He said:

> That made me angry sitting there. [When mom] spoke up and said "I usually hold her when you guys gavage her". I don't know, it's our child and I feel that if [mom[wants to hold her when she's [the nurse] gavaging her or if I want to hold her I think it's all right you know. And when she [the nurse] straight up [straight forward] said, "Well you're going to have to wait till I'm done feeding her". It kind of - it didn't kind of - it did upset me, it did. I was like "NO".

Nurturing their infant was part of feeding their child. The father was trying to support the mother in the importance of holding their daughter. By focusing only on the infant's nutrition and ignoring the comforting and nurturing roles of the mother, the nurse ignored the family as a unit.

These families' worries and their feelings when they attempted to be part of their infant's care, are consistent with the research on parenting an infant in a high technological nursery (Kasper & Nyamathi, 1988). In the NICU, being unable to hold their infant, feed, and care for their infant had new significance for parents and became a source of distress. Health care providers need to focus not only on the tasks of caring for the ill neonate, they also need to try to incorporate the needs of the family.

Protectiveness

Parents felt the need to be vigilant, a guardian, and know what was going on, and they felt a need to fulfill their role as protector from harm when they felt their infant was in pain. Fathers and mothers watched, questioned and talked about protecting their infants

from pain, threats to life, and future pain. One father spoke about what it was like to see care givers handling his daughter. He said:

> I think she was feeling the nurses handled her a little rough...moving her and not taking into consideration those chest tubes because whenever they'd do it she would cry and they weren't as gentle as the others.

After watching how others handled her daughter, one mother said how she would handle her baby:

> Well, it's, uh, she's so small and fragile. It's the way they move her. Her head's so tiny. If I could pick her up I would cradle it with both hands and gently move it slowly. They pick her head up with one hand like it was an orange and put it where they want it. Rather than gently allowing her to move with their help.

The father continued: "Yeah, I like her whole body to be moved like that, instead of moving her head, then her body."

The mother finished: "She's so fragile she needs to be handled gently, like we would handle her."

Finally, one family described what their newborn might experience in her future (Family E). After the surgical repair of her daughter's gastroschisis defect the mother said:

> Well, I don't know if that will, I mean, right now, her mental capabilities, you know, I know she can't, she's not going to really even think about it as she's growing up too much except for the scar. That's another thing that kind of gets to me, for 'A', you know. I'd like it, I'd like for her to lead a normal life and I'm sure she's going to lead as normal as possible. But with he second operation then they (the second closure) heal from the inside out instead of stitching it up so there's going to be a bigger scar. And uhh, with the fact unless she had, you know, cosmetic surgery, she's not going to have a belly button, you know.

The father continued:

> There won't be any...she's going to be like every other child but on the other hand

> she's not going to be like every other child. I don't want it to affect her when she grows up but I don't know how that's going to go whether there'll be any...

The mother went on to say:

> How can you prevent it? Hurt, pain, it's going to take a lot of work as she grows up to make her feel good about herself so that she's confident enough with her own body to be able to accept that. You know, she's going to have to realize that when she's a kid in Jr. High/High School and when the kids all take showers together she's going to be teased and people are going to ask her questions and you know make fun of her and that's...It's a cruel world for little kids and there's always somebody that gets picked on and I'm just afraid that she's going to be the one that gets picked on. It's a different kind of pain.

These parents did not distinguish between their daughter's physical and emotional pain. They talked about the meaning of pain in their child's future and how they might anticipate and protect her from pain.

Trust

Several parents alluded to the ability to trust what they saw, understood, or believed was true for their experience. Trust was based on the information exchanged between caregivers and families. If families were told one thing and another happened, they became more vigilant. If families experienced what they were told would happen, their trust of caregivers gave a positive meaning to their experience. These families were less questioning about what happened to their child.

One family (Family A) whose daughter's initial diagnosis was changed and who had two surgeries, was also the family whose daughter experienced a one day delay in removal of her chest tube. The father questioned the health care providers extensively and once even followed a surgeon out of the nursery because they were determined to obtain all the information. This family's encounters with health care providers had negative

undercurrents. When the family was asked what made them feel so helpless, the father said:

> You know, because they they [surgeons] - this is their job not to tell everything. You know to worry the parent. I don't like it because I told them going in that I want to know everything...I've done homework on this from diaphragmatic hernia all the way down to all her treatments and so I wanted to know exactly how she was progressing, pain anything.

The family struggled with believing if the information given, was true, and whether all information was being shared. When parents were asked at their infant's bedside, "What do you see?", the father said: "A baby that needs to be home. She needs to be home with her brothers and sisters...".

These parents just wanted to take their daughter home and be a family. They had struggled with their daughter's diagnosis, surgeries, and her pain. The safety that family offered to their daughter was in their thoughts.

In contrast, one family (Family F) whose son had experienced respiratory distress soon after birth and was transported from an outlying hospital to the NICU, expressed their trust in health care providers. The father said:

> Uhm, you put a lot of trust into the care providers. And I know it's very difficult with such a small subject on, you know, being able to either draw blood or doing all of those little things [stabilizing the infant for transport].

Their son improved and talking about what they experienced in the NICU, the mother said:

> Well, you know you'd seen him one day with all this stuff and then next time, I guess you expect to see him the way you left him and it was it was nice that it was good stuff we'd see when we'd come back.

The father continued:

> And plus talking with the doctors and even the nurses that he was - it seemed to be progressing [their son's condition] a little bit faster than the timetable that we were given. We were given a timetable of maybe nursing by Wednesday/Thursday and all of a sudden we got to nurse Tuesday and so those types of little things [signs of getting better].

The care providers had explained the course that their son might experience in his recovery. This family saw not only that their son's course met those expectations, but their son progressed faster than even the providers had thought he would. The parents' trust did not blind them to their son's pain, but they did not express any feelings of helplessness or distress with their son's stay in the unit.

Families observed and gathered information and gave meaning to these observations. When their observations were supported by the information providers gave, trust was established. This trust radiated into other areas. Parents who felt they could trust providers to care for their child and put their child's best interest at heart, did not feel so helpless when they placed their child's health in the care of provider's hands. The family's distress was diminished, and they found less need to feel protective.

Empathy

Babies communicate their needs through sounds and behaviors such as crying and fussing. Parents and nurses have to learn an infant's language of communication in order to respond to the communication. The very act of empathy is a reciprocal process. When an infant cries, it can be pain and discomfort from an incision or it can be hunger. In order to respond appropriately, parents imagine what they would feel and try to place themselves in the infant's situation. Infants in the NICU do not respond the same as healthy full-term infants. However, families who spend time at their child's bedside

become attuned to what their child is communicating. The families in this study exhibited a capacity to understand what their infant communicated.

Mothers and fathers told how they empathized with their infants. One mother, after her daughter's second surgery (Family E), said:

> I think it - I think it's hard for her. Before when she cried she would be picked up and now that she can't be picked up. To pick her up would hurt her but she still wants to be held (pause) and I can't.

This mother was caught between comforting or causing pain if she held her daughter. She understood her daughter's need to be held and how hard it must be for her daughter because she could not hold her. Before surgery, the mother had comforted her daughter by holding her. Now unable to hold and comfort her, the mother expressed the empathy she felt for her daughter.

Another mother described how it must have been for her son as she watched him struggle for breath. She said:

> He was really laboring and that was hard to watch him work so hard to breathe. You don't know, I don't know, I mean the oxygen it really wasn't working, I mean he was still just - his poor little chest would just cave in and I just - I don't know. I just felt really sorry for him, he was having to work so hard to get that breath. I just - I felt bad for him, it was such hard work for him.

This mother understood how hard it was for the infant to take a breath. She recognized his struggle for breath and understood what that meant for him. Her use of "his poor little chest" and her sensitivity to the "hard work for him" demonstrated her empathetic understanding.

For infants who experience the pain of the NICU, it is important that parents are sensitive to their infant's cues. In their study on infant pain in the NICU, Grunau and

colleagues (1994), found that parents' empathy was needed for their child's optimal developmental growth. Graham (1993), in her research on parental sensitivity to infant cues, discovered that empathy was the best predictor of sensitivity to infant cues. If parents lacked empathy they had a difficult time interpreting their infant's cues and were unable to respond appropriately to their child's needs.

The parents in this study described their infant's pain in the context of the whole experience of having an infant in the NICU and what it meant to be a parent to that infant. Families talked about what they expected to see when looking for pain in their infants, what they did or did not see as pain in their infants, and the meaning of the pain experience for the infant and family. These parents wanted more than anything to be a parent. It is important that health caregivers realize that families come with knowledge and experience from parenting other children. Nurses have knowledge and skills in treating pain and caring for vulnerable infants. By sharing their knowledge and understanding, nursing and families can mutually promote the family.

Chapter 5

SUMMARY

The purpose of this study was to expand our knowledge of parents' understanding of their infant's pain while in neonatal intensive care, and the meaning and value parents place on those experiences. The study used a qualitative design based on grounded theory to collect data from seven sets of parent dyads, whose infants were hospitalized in neonatal intensive care.

Parents entered the NICU with preconceptions of pain based on their previous experiences. They expected their infants to experience pain while hospitalized. Parents anticipated pain to be caused by surgery, chest tubes, and wound infections. The parents reported that they would look for crying, wrinkled faces and eyebrows, and leg movements as indications their infants were in pain. These preconceived ideas were used to establish the presence of pain in their premature or ill infants. Parents described crying, facial grimacing or bunching, frowning, and wrinkling, body twitching and legs drawn up tight, as signs of pain in their infants. They identified major and minor surgery, chest tubes, requiring a ventilator, gavage feeding, heel sticks, and handling as sources of pain for their infants. Parents described their infants' pain on a continuum from minor to life threatening and from discomfort to very painful. They talked about pain in terms of intensity, using what they had learned about pain from their older children. Parents also considered that happy, peaceful sleeping infants were not in pain. When they were unable to perceive the cause, parents sometimes expressed uncertainty as to whether their infant's behaviors were a result of pain. Some behaviors were attributed to their infant

being tired, mad, hungry, groggy, or dreaming.

Parents' interpretation of infant pain is based on their preconceptions formed after their previous experiences with pain and the experiences of pain in their other children. The parents' experiences when their infant is subjected to pain while hospitalized, and the information about infant pain provided by care givers is continuously adding to their interpretation of their infant's pain. Parents described their helplessness and distress at seeing their infant in pain and being unable to control or stop their infant's pain. They related their fear that their child might not survive. Trust was an underlying component of the meaning of the NICU experience. They talked about the protective feelings and empathy they felt for their child, and described the need to comfort and nurture their son or daughter.

Strengths and Limitations of the Study

This study provides a beginning theoretical base for future research. The qualitative method captured rich descriptions of parents' experiences and complex understandings of families whose infant has experienced pain. Previous research has focused solely on mothers with infants beyond the neonatal period. This study captured both mothers' and fathers' perceptions of neonatal pain.

However, data were collected using only one tertiary care facility, though drawing from a large geographical area. The sample size of seven parent dyads was small, and subjects were primarily Caucasian. To determine the generalizeability of the perceptions of these parents, a survey study could be conducted. A closed-ended questionnaire based on the results of this study and administered to a similar population, first time parents,

and parents with differing ethnic and racial backgrounds would provide additional data on this understudied subject.

Conclusions

To appreciate the full meaning of what families face when their infant is in pain, the effects of parenting a neonate hospitalized in the NICU needs further study. Nevertheless, the study provides beginning data on parents' perceptions about infant pain in neonatal intensive care. It is important for neonatal nurses to have an accurate understanding of parents' perceptions of their infants' pain. Nurses need to assess parents' assumptions, and inform parents of the wide range of behavioral responses to pain an infant can display, the many causes of pain in hospitalized infants, and the specific needs of their infant. Nurses need to be well versed in the development of the parenting role and support families in the NICU.

Parents should not have to ask permission to care for their infant. They need to be encouraged and indeed expected to provide care to their infant in their own way. Fostering a sense of competent parent-infant interactions is essential. Nurses have a pivotal position in supporting families in the NICU. They must support the family roles of providing protection, security and safety. Nurses must assess parents as parents, not just as an extension of the infant.

Trust between family and health care providers relies on nurses' ability to broker meaningful communication. Families not only need accurate information, but they also need to know what effect that information will have on their infant and their family. Nurses must encourage and support families to participate and parent even the most

fragile and ill newborn. The reality is that the NICU becomes the home or place to care for their child. It is hopefully only a temporary home but still the only place where parents can fulfill their early tasks and duties.

In order to educate parents about the specific needs of their infant, nurses must become familiar with the causes of pain and the wide range of behavioral displays which infants of varying gestation and severity of illness can manifest. Nursing interventions should view the infant and family as one. The family is the one constant in the infant's life. In the technological environment of the NICU the critical management of neonates tends to emphasize the present. Parents, however, view their infant in the context of the past, present and future. They describe the pain experience as inclusive; their infant's pain becomes their pain. Neonatal nursing has begun to master the care of the infant in pain; now we must begin to develop a global awareness of the family in pain.

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of parents. Children's Health Care, 20, 19-25.

Appendix A

Glossary

Glossary

Pain/Nociception: In the term and preterm infant, nociception is used interchangeably with pain. Nociceptive activity refers to the neural pathways for pain, both sensory and cortical. According to Anand and Hickey (1987), "pain is a sensation with strong emotional associations".

Neonate and Infant: Neonate describes a newly born infant less than 4 weeks of age. Infant describes the period of time from 1 month to 12 to 14 months of age. (Dorland's illustrated medical dictionary, 1974). For the purposes of this study, these terms are used interchangeably.

Term Infant: Infant born after 37 weeks gestation (Gamely, 1994).

Pre-term Infant: Infant born prior to 37 weeks gestation (Gamely, 1994).

Family: "Family refers to two or more individuals who depend on one another for emotional, physical, and/or economic support. The members of the family are self-defined" (Boyd & Hanson, 1996).

Family Function: Family function is the purpose that the family serves in relation to the individual, the family, other social systems, and society. Function refers to how families go about meeting the needs of individuals and meeting the purposes of the broader society in general (Boyd & Hanson, 1996). According to Friedman (1992), the significant functions of the family include affective function, socialization or child rearing function, and health care function. The affective function involves the family's protection, support, and care of the psychosocial needs of it's members. Socialization, or the child rearing function, involves the family's teaching children how to function and

assume adult roles in society. The health care function involves the family's responsibility for meeting basic economic needs of food, clothing, shelter, and health care (Friedman, 1992).

Level II Nursery: Provides management of small, sick neonates with a moderate degree of illness (Freeman & Poland, 1992).

Level III Nursery: Provides management of neonates of all risk categories that may require sophisticated care, such as those with severe immune or non-immune hydrops fetalis, or fetal anomalies including congenital heart disease, open neural tube defects, abdominal wall defects, or diaphragmatic hernia (Freeman & Poland, 1992).

Appendix B

Demographic Questionnaire

Demographic Questionnaire

1. Ages: Subject A._____

Subject B._____

2. Sex of Subjects:

A. female _____ male _____

B. female _____ male _____

3. Educational level of subject A: (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 17+

Graduate School: 17 18 19 20 Masters Doctorate

4. Education level of subject B: (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 17+

Graduate School: 17 18 19 20 Masters Doctorate

5. Occupation of subjects: A._____

B._____

6. Ethnic background of Subject A:

a. Caucasian _____ b. African-American _____

c. Hispanic _____ d. Asian _____

e. Native American _____ f. Pacific Islander _____

g. Other_____(please specify)

7. Ethnic background of Subject B:

a. Caucasian _____ b. African-American _____

c. Hispanic _____ d. Asian _____

e. Native American _____ f. Pacific Islander _____

g. Other_____(please specify)

8. Religious Affiliation of subject A:

a. Protestant _____ b. Catholic _____

c. Muslim _____ d. None _____

d. Other_____(please specify)

9. Religious Affiliation of subject B:

a. Protestant _____ b. Catholic _____

c. Muslim _____ d. None _____

d. Other_____(please specify)

10. Present Marital/Partner status:

a. single (never married)_____ c. married_____

b. partnered, not married _____ d. widowed _____

11. Location of your home:

a. Within Portland-Metro area _____

b. Outside Portland-Metro area ____

c. Outside Oregon _____

12. Relationship of subject A to infant:

a. Mother _____ b. Father _____

c. Grandparent _____ d. Aunt _____

e. Uncle _____ f. Other relative_____

g. Roommate/housemate_____ h. Other_____

13. Relationship of subject B to infant:

a. Mother _____ b. Father _____

c. Grandparent _____ d. Aunt _____

e. Uncle _____ f. Other relative_____

g. Roommate/housemate_____ h. Other_____

Appendix C

Interview Guide

Interview Guide

"Hello, my name is _____, and I am a graduate nursing student at Oregon Health Sciences School of Nursing I spoke with you previously about the interest I and my colleagues have in learning parents' understandings of the pain their baby experiences while hospitalized in the DNCC. We are doing research on this subject because we feel parents are important resources about their babies and can help nurses better understand the special relationship that they have with their babies. I would like to ask you eight questions now and three more when we are at your baby's bedside. The interview should take about one hour. If I ask a question that you would rather not answer, that is all right, we will go on to another question. You may also decide to stop participating at any time, we will then destroy any information you have already given us. Are you still interested in participating in the interview?"

"I would like to tape record the interview. The tape will only be used by the research team to record your thoughts and ideas, no one else will have access to this information. All identifying data will be kept separate and locked. The tapes will be destroyed when the research project is finished."

The first set of questions are as follows:

1. Describe an incident when you thought your baby was in pain.

2. During that incident, describe what your baby did that made you feel he/she was in pain.

3. What things did you feel caused your baby to be in pain at that time?

4. Explain some of the things your baby did to let you know she/he was in pain.

5. What did you think made your baby's pain go away?

6. How did it feel to you when your baby was in pain?

7. What and/or who helped you understand your baby?

8. Is there anything I should have asked that I didn't ask?

The questions for the bedside interview are as follows:

1. Tell me how you feel your baby looks right now.

2. Tell me about anything you see that makes you feel your baby is in pain or is not in pain.

3. Is there anything else you would like to say about your family, yourself, or your baby?

Appendix D

Consent Form

IRB#: 4224
Approved: August 24, 1996

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form

TITLE

Parents' Perception of Their Infants' Pain While Hospitalized in Neonatal Intensive Care

PRINCIPAL INVESTIGATORS

Ramona J. Granath R.N., B.S.N. (503) 494-8122
Patricia C. Rhay, R.N.C., B.S.N.
Juliana M. Campbell R.N.C., B.S.N.
Vivian Gedaly-Duff R.N., D.N.Sc.
Department of Family Nursing

PURPOSE

You have been invited to participate in this research project because you recently had a baby hospitalized in a newborn intensive care unit. The purpose of this study is to learn more about how families understand and recognize their infant's pain experience. We want to use this information to develop new ways to teach nurses and doctors how parent's understand their infant's pain.

PROCEDURES

We will ask you to complete two questionnaires.
1. The first questionnaire you will fill out asks some common demographic items about your family's medical and social history.
2. The second questionnaire will be done with the investigator and will ask questions about your family's medical and social history.
There will be an interview with two parts.
1. Part one of the interview will be done away from your baby's bedside at a place agreed upon by you.
2. Part two of the interview will be done at your baby's bedside.
The interviews will entail asking questions about your baby's experience of pain. The questionnaires and interviews will take one hour. With your permission, we will tape record the interviews. All of the above information will be kept strictly confidential.

RISKS AND DISCOMFORTS

There may be several.
1. Possible inconvenience to you related to the time required to complete this study.
2. It might be upsetting to talk about what it is like to have your baby experience painful situations.
3. You and your spouse/partner may disagree regarding the interpretation of your baby's pain.
This may cause some conflict.
If you feel too upset to talk, we will stop the interview.

BENEFITS

You will not personally benefit from participating in this study. However, by serving as a subject, you may contribute new information about newborn pain which may benefit patients and families in the future.

ALTERNATIVES

You may decide not to participate in this research study.

CONFIDENTIALITY

We will keep the information you give us confidential. Neither your name nor your identity or that of your baby will be used for publication or publicity purposes. We will change identifying details if information you have given us could cause you or your baby to be identified by someone familiar with this case. Only the research team will have access to the information. All identifying data will be kept separate and locked. Audio tapes will be destroyed upon completion of this research. According to Oregon law, suspected child or elder abuse or neglect must be reported to appropriate authorities.

COSTS

There will be no costs to you for participating in this study.

LIABILITY

The Oregon Health Sciences University, as a public corporation, is subject to the Oregon Tort Claims Act, and is self insured for liability claims. If you suffer an injury from this 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. However, you have not waived your legal rights by signing this form. If you have further questions, please call the Medical Services Director at (503) 494-6020.

PARTICIPATION

Ramona J. Granath, Patricia C. Rhay, and Juliana M. Campbell at (503) 494-8122, have offered to answer any other questions you may have about this study. If you have any questions regarding your rights as a research subject, you may contact the Oregon Health Sciences University Institutional Review Board at (503) 494-7887. You may refuse to participate, or you may withdraw from this study at any time without affecting you or your child's relationship with or treatment at the Oregon Health Sciences University. If you decide to stop we will destroy any information you have already given us. You will receive a copy of this consent form. Your signature below indicates that you have read the foregoing and agree to participate in this study.

_____

Subject's Signature Date

_____

Witness's Signature Date

_____

Investigator's Signature Date

Appendix E
Human Subjects Approval

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: August 24, 1996

TO: Ramona Granath, BSN SN-ORD
c/o Patricia Rhay

FROM: The Committee on Human Research
MacHall Rm. 2160, Ext. 7887

SUBJECT: IRB#: 4224
TITLE: Parent's Perceptions of Their Infants' Pain While Hospitalized in Neonatal Intensive Care

This confirms receipt of the revised consent form(s), and/or answers to questions, assurances, etc., for the above-referenced study.

It satisfies the requirements of the Committee on Human Research. The protocol and proposal to use human subjects are herewith approved. The IRB# and the date of this memo must be placed in the top right corner of the first page of the consent form. This is the approval date of this revised consent form.

Investigators must provide subjects with a copy of the consent form, keep a copy of the signed consent form with the research records, and place a signed copy in the patient's hospital/clinic medical record (if applicable).

Approval by the Committee on Human Research does not, in and of itself, constitute approval for implementation of this project. Other levels of review and approval may be required, and the project should not be started until all required approvals have been obtained. Also, studies funded by external sources must be covered by an agreement signed by the sponsor and an authorized official of the University. The Principal Investigator is not authorized to sign.

If this project involves the use of an Investigational New Drug, a copy of the protocol must be forwarded to the Pharmacy and Therapeutics Committee (Pharmacy Services - Investigational Drugs, OP-16A).

Thank you for your cooperation.