Life-Support Decisions Involving Imperiled Infants

by

Lucia D. Wocial

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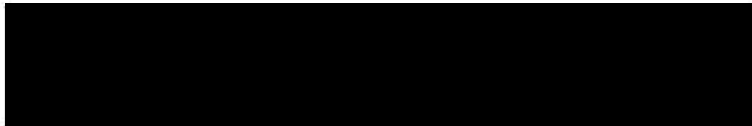Doctor of Philosophy

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APPROVED

Virginia Tilden, R.N., D.N.Sc., F.A.A.N., Professor, School of Nursing, Oregon Health Sciences University, Research Advisor

Marsha Heims, R.N., Ed.D., Associate Professor, School of Nursing, Oregon Health Sciences University, Committee Member

Michael Garland, D. Sc. Rel., Professor, Department of Public Health and Preventive Medicine, Oregon Health Sciences University, Committee Member

Kathleen Potempa, R.N., D.N.Sc., F.A.A.N., Dean, School of Nursing, Oregon Health Sciences University

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Abstract

TITLE: Life Support Decisions Involving Imperiled Infants

AUTHOR: Lucia D. Wocial

APPROVED: *Virginia P. Tilden*

Virginia Tilden, RN, DNSc, FAAN,

This research explored the experiences of parents in the
Neonatal Intensive Care Unit (NICU) who faced the dilemma of
withholding and/or withdrawing (W/W) treatment from their infants.
The central research question was "How do parents describe their
experience with and understanding of the decision-making process
used to consider W/W treatment from their infants in the NICU?"
The aim of this research was to answer these questions: 1) How do
parents feel about their involvement in the decision-making process?
2) What information was important to parents in reaching a decision
about W/W treatment from their infant? 3) What meaning did
parents give to comments, advice, and behaviors of health care
providers involved in the process? A blending of content analysis and
phenomenological techniques was used to conduct open-ended focused
interviews and analyze data generated from those interviews. Clear,
accurate, and timely exchange of information helped parents to
perceive their experience as positive. When providers demonstrated
that they cared, it helped promote trust between providers and parents,
and promote parents' confidence in the information and the final

decision. The crucial message found in all the themes significant to the study aims was that parents want to be parents. Parents are able to fulfill their ethical obligations to their infants if they are actively involved in discussions to consider limiting treatment options for their infants.

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Chapter 1: Introduction

When most parents anticipate the birth of a baby, they expect the experience to be filled with joy. They anticipate their first moments with their baby, holding it in their arms, spending quiet private time with a healthy new member of their family. Few parents are prepared for the possible unexpected outcomes of pregnancy.

The baby may arrive prematurely to face a long, hard road in a neonatal intensive care unit (NICU). Instead of holding their healthy full-term baby in their arms, parents may find the baby in the NICU surrounded by loud, unfamiliar, frightening equipment with alarms. Instead of contemplating how they will ever sleep for the noise of their vigorous new baby, they find themselves wondering whether or not they will ever hear the baby cry, or hold it in their arms. Instead of being surrounded by family and friends, they are greeted by strangers who tell them their baby is critically ill. They face the agonizing situation where they must consider withdrawing or withholding (W/W) treatment from their baby. This is what we as health care providers often refer to as an "ethical dilemma."

Most expectant parents anticipate their new role. They worry about their duties as parents. They think about their responsibilities which include not just caring for and about their new babies, but also a duty to support their baby and do what is best for him or her. In the NICU, the intimate task of parenting must be shared with health care providers. Parents' ability to fulfill their obligations to their baby

completely depends on the context, clarity and manner of communication with these health care providers.

Studies that focus on family experiences with ethical decision-making are underrepresented in the nursing literature (Chafey, 1992). The present research focuses on the experiences of families in the NICU who suffered the death of their infants after facing the dilemma of considering W/W treatment from their infants. Of all the members of the health care team, nurses have the most extensive contact with families in the NICU, yet know little about what they experience during the crisis of considering W/W treatment from their infants.

Since the well-publicized case of Baby Doe in 1982, and more recently Baby K in 1993, debate and controversy have surrounded the care of imperiled infants in the NICU. Much of that debate has centered around treatment decisions physicians face and the role nurses should perform in the decision-making process. More recently, this debate has shifted not just to who should be involved in the decision-making process, but to who should be responsible for the final decision, ethics committees, physicians, or parents (Campbell & McHaffe, 1995; Carter, 1993; Lantos et al, 1994).

While the debate over the extent of involvement for ethics committees in resolving life-support decisions for infants continues, there is general agreement that their role in the process should be advisory only. Most experts agree that parent preferences should at the very least be considered by physicians as they contemplate the options

of W/W treatment from infants. However, they fail to agree on the weight these preference should bear on the final decision. Experts (Fost, 1986; Kraybill, 1988; Lantos et. al., 1994; Pinch & Spielman, 1990) agree that, while parents will live with the outcomes of these decisions, there is little empirical information about what parents experience when their infant is the center of an ethical dilemma.

At least three significant developments in the past 25 years have shaped the course of neonatal care in the United States : 1) rapid increase in the number of NICUs, 2) rapid development of medical technology, and 3) enactment of the laws and regulations that apply to the care of imperiled infants. In 1965 only 16 NICUs were operating in the US. (Pinch & Spielman, 1989). By 1988, 650 and by 1992, 1183 neonatal units existed with a total of 18,205 beds in the US. (American Hospital Association, 1994). The rapid increase in available services suggests a growing number of imperiled infants, and consequently a significant number of families will experience the crisis of an NICU admission each year, yet very little research has explored this phenomenon.

Advances in modern technology have made it possible to care for infants who weigh as little as 500 grams or whose gestation is a brief 24 weeks instead of the usual 40 weeks. While survival rates increase with increasing birth weight and gestational age, recent studies indicate that survival may be associated with significant morbidity.

One study determined that children whose birth weights were below 750 grams show significant impairment of cognitive ability, psychomotor skills, and academic achievement (Hack, Taylor, Klein, Eiben, Schatschneider, & Mercuri-Minich, 1994). Another study determined that 22 of 42 children born at less than 29 weeks of gestation had moderate to severe disabilities at age 4 (Johnson, Townshend, Yudkin, Bull, & Wilkinson, 1993). There are no uniform tracking or reporting requirements for infants treated in NICUs. This gap in data collection has resulted in a lack of reliable statistics on survival rates or morbidity for term or near-term infants born with congenital anomalies and/or serious illness. Evaluating the true impact of modern technology on the care of imperiled infants is hampered by the absence of a consistent systematic tracking system for infants who receive care in NICUs in the U. S..

The current trend in US. hospitals, documented in the literature (Caplan & Cohen, 1987) and confirmed by personal experience as an NICU nurse for several years, favors an approach that requires treatment for all imperiled infants. This trend has shifted decisions away from whether or not to initiate treatment to W/W treatment later in the neonatal period (Caplan & Cohen). The implication is that while choosing to forgo treatment at the outset may be decisive, it is too quick and relies heavily on intuition, and that initially treating all infants is a more reasoned approach.

Withdrawing treatment, because it requires a directed action may be more difficult for clinicians that withholding treatment, which can be accomplished with inaction. Delaying decisions to withdraw or withhold treatment leads to a more cautious and tentative decision-making process. This approach can result in an unnecessarily prolonged waiting period and protracted decision-making. One can assume that this approach has consequences for families and health care providers, but there is no research to demonstrate this.

Strongly held social views and a political climate that supports them can have a major impact on health care policy. In 1982, a highly publicized case of an infant born with Down syndrome and esophageal atresia brought to a head a long-running debate in health care ethics over the care of imperiled infants. Based on the medical opinion of the attending physician, the parents of this infant declined to give consent for surgery, and he subsequently died (Rhodes, 1990). His death led to a political controversy over passive euthanasia in NICUs and, thanks to a political climate that supported extreme right-to-life views, eventually to the enactment of "Baby Doe" regulations (Cohen, Levin, & Powderly, 1987). The controversy and publicity around these regulations forever changed how treatment decisions would be made in NICUs (Newman, 1989).

Supporters argue that the regulations were designed to protect the rights of handicapped newborns (Lantos, 1987). Opponents believe the regulations have undermined the decision-making process (Bailey,

1986). The wording of the actual regulations allows some flexibility in providing treatment to imperiled infants, but the guidelines that accompany the law are less flexible. These suggested guidelines provide specific examples of when it is and is not appropriate to limit treatment to these infants.

While the regulations carry the weight of the law, the guidelines do not, and they have contributed to some confusion over how to apply the regulations to imperiled infants. A majority of professionals surveyed believe that the regulations contribute to over treatment of imperiled infants, are not necessary to protect infants' rights, interfere with parents' rights to determine the best interests of their children and do not allow infant suffering to be considered adequately when making treatment decisions (Kopelman, Irons & Kopelman, 1988). Parents and health care providers who remember the publicity surrounding Baby Doe cases and the Baby Doe hot-lines may believe that no options for treating imperiled infants exist, other than providing full life-support measures. Fears about media attention and legal battles may prevent parents from seeking alternative choices, and prevent providers from doing what they feel is best for an infant.

In Virginia, a case that involved the care of a baby born with anencephaly has confirmed those fears and has sent shock waves through the community of people who care for and about imperiled infants and children. Anencephaly is a congenital anomaly in which the residual brain at the base of the skull is amorphous and the skull is

missing (Holzgreve & Beller, 1992). Infants with this condition are in a state similar to a persistent vegetative state in adults. In the Virginia case, despite the recommendations of attending physicians, an ethics committee, and a court-appointed guardian for the infant known as Baby K, that the infant not receive life-prolonging treatment, her mother continued to request all means of treatment necessary to keep her child alive. The case was settled in the courts. The courts ruled that Baby K's mother's requests be honored.

While not written specifically to provide protection for imperiled infants, the Americans with Disabilities Act (ADA), among other laws was used to justify the mother's requests and require physicians to continue treatment (Fry-Revere, 1994). The ADA was enacted by Congress to establish general rules of nondiscrimination concerning the disabled. One interpretation of the ADA prohibits public institutions, such as hospitals, from discriminating against individuals on the basis of their disability. Baby K's lawyers successfully argued that anencephaly was a disability, not a condition inconsistent with life, and that because it was a disability, the hospital could not deny her emergency services because of her anencephaly.

The Baby Doe case was an example of conflict between the group of decision makers most directly and intimately affected by the outcome of the decision and community members who are neither directly nor intimately affected by that outcome. The case of Baby K illustrates the more acutely felt conflict when decision makers disagree

among themselves and must turn to outsiders, in this case the legal system, to resolve their conflict. There is little research to indicate how best to intervene in such situations, but clearly nurses are likely to find themselves involved in the middle of them. Little is known about how the nurses caring for these infants and their families were affected by the ethical dilemmas of either case, or the extent to which the nurses participated in the ethical decision-making process. It is clear, however, that nurses face less highly publicized but equally troubling cases daily in the practice of neonatal nursing.

Whether or not there is conflict between health care providers and parents, complex ethical dilemmas that center around saving the life of an infant have a significant impact on nurses. Within the confines of an ill-defined role in the ethical decision-making process, nurses must wrestle with their own feelings about such weighty issues and simultaneously give bedside care to the infants in question and help support their families through this difficult time.

Exploring families' experiences with the decision-making process may sensitize health care providers to families' perspectives and improve providers' understanding. Also, it will help nurses deal with their own internal struggles around these troubling decisions by challenging them to clarify their own values and examine how those values affect their role in the decision-making process. In addition, this exploration will provide nurses with information they can use to

define their role in helping parents to meet their ethical obligations to their infants in such situations.

The close contact nurses have with families and the intense care they provide to infants give them unique knowledge relevant to treatment decisions. This knowledge, combined with their position as members of the health care team, may help them facilitate parental involvement and collaboration among decision makers who must resolve ethical dilemmas in clinical practice. Nurses need research-based knowledge to guide the care they provide to imperiled infants and to families who face ethical dilemmas regarding life-support for their infants.

The purpose of this study was to improve understanding about and appreciation for what families experience. Rather than generate specific theories about how best to work with families, this research focused on how parents describe their experience with, and their understanding of the decision-making process used to consider W/W treatment from their infants in the NICU.

Chapter 2: Literature Review and Theoretical Framework

The body of literature relevant to resolving ethical dilemmas in neonatology is extensive. However, the bulk of it is opinion based, abstract, and theoretical. It also fails to examine the process of ethical decision-making or the roles of participants in the process. There is a small but growing body of empirical research in this area. While some of it focuses on families, most of it relates largely to physicians' and nurses' experiences and has little application to what parents experience. Following is a brief review of literature relevant to what parents may experience and their perspectives on the decision-making process used to resolve ethical dilemmas in the NICU.

Review of the Literature

Non-research-based literature contains many powerful anecdotes about infants' and parents' experiences in the NICU (Gustaitis & Young, 1986; Lyon, 1985; Shelp, 1986). The most compelling stories come directly from parents (Barthel, 1985; Bridge & Bridge, 1981; Harrison, 1986; Stinson & Stinson, 1983). One especially poignant example is a parent's description of the details of her deformed infant son's short life (Harrison, 1986). After the parents refused to consent to treatment for their son, believing that it was not in his best interest, the attending physicians obtained a court order to continue treatment. The parents describe visits with their son, at which they would find him screaming in pain and tied to his bed to prevent him from pulling at his multiple surgical wounds. Before

doctors could transfer the infant to a state hospital for long-term care, he died.

Equally powerful, but fewer in number, are stories of parents requesting treatment for their imperiled infants which health care professionals felt was inappropriate. Two notable cases have been described in the popular press, the Lakeburg conjoined twins and Baby K. In both cases, parents desired treatment that attending physicians felt was inappropriate. The Lakeburg twins were eventually treated at another hospital where physicians felt they could benefit at least one twin with treatment. Both twins eventually died. One twin died during surgery to separate her from her sister. The surviving twin remained on a ventilator her whole life, which lasted just short of one year. Baby K received treatment at a long-term care facility until April of 1995. Despite physicians' objections, but consistent with court-ordered emergency treatment, Baby K was taken by ambulance to her hospital of birth after suffering a cardiac arrest following contraction of pneumonia. After 30 minutes of resuscitation efforts, she was pronounced dead (Paris, Miles, Kahman, & Reardon, 1995).

Both types of stories illustrate the anguish caused by conflict in the decision-making process used to resolve life-support decisions for imperiled infants. The central concerns in these two cases revolve around many complex issues, including medical futility, quality of life, sanctity of life, meaning of life, allocation of scarce resources, respecting the conscience and expertise of health care providers, and the rights

and roles of parents to act as ultimate decision makers for their children. The conflict evident in these two publicized cases seems to be rooted in these fundamental differences in values, but also might stem from poor communication. Clearly the conflict is very easily exacerbated by communication difficulties.

Parents' lack of knowledge is reported by physicians to be a factor prompting them to present limited treatment options and restrict information given to parents. This is a common strategy used by physicians to protect parents from the stress of decision-making (Anspach, 1993; Fost, 1991; Harrison, 1986) and presumably to minimize any guilt associated with having to make such a momentous decision. Some research indicates that patients fail to understand the meaning of medical terms and that physicians often overestimate what patients understand (Charney, 1972). One wonders if this communication breakdown is due to strategies that encourage providers to restrict the information they provide during discussions about treatment options. A growing body of literature suggests that parents want more information from physicians and a more active role in the decision-making process regarding treatment options for their infants (Able-Boone, Dokecki, & Smith, 1989; Harrison, 1993; Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990; Kirschbaum, 1996).

When researchers examined the perceptions of communication processes between parents of children with special needs and health care providers in the intensive care nursery, some clear preferences

emerged (Able-Boone, Dokecki, & Smith, 1989). Parents wanted to be involved in decisions about their infants. They preferred that care providers be direct and honest with them. To avoid confusion from hearing conflicting information from different members of the health care team, parents wanted one person to coordinate all the medical information in such a way that their baby was seen as a whole person and not a conglomeration of separate body systems.

Some research results indicate a troubling discrepancy in perceptions about communication between health care providers and family members of patients. Using a Likert Scale to rate parents' and family members' needs from least to most important, one study found that parents of critically ill infants scored their needs, including that for honest communication, as more important than the nurses' scoring of parents' needs (Jacono, Hicks, Antonioni, O'Brien, & Rasi, 1990). One might then assume that nurses are making assumptions about parents' needs without confirming them. If nurses underestimate parents' communication needs, it is reasonable to assume that the needs may not be fully met. Since open, accurate communication is a crucial part of collaborative ethical decision-making, failing to meet parents' communication needs may have serious consequences for ethical decision-making.

In a recent study that investigated which physician and nurse behaviors were beneficial and which were burdensome in the context of decision-making about withdrawing life-sustaining treatments,

Tilden, Tolle, Garland and Nelson (1995) found that families identified communication and information transmission as having influenced the decision-making process. Intensive interviews of surrogate decision makers for decisionally incompetent adults for whom treatment was withdrawn revealed that families were not only eager for more information, but desired early, honest, and direct talk about poor prognosis. The results of this research support the notion that effective, open communication benefits families who face the crisis of deciding whether or not to withdraw treatment from an incompetent family member.

Other studies that examined various aspects of physician/patient perceptions about treatment choices show that physicians can substantially misunderstand patients' goals for treatment. Two studies (Wenger, Oya, Teno, Phillips, Layda, Lynn, Califf, & Dawson, 1992; Schneiderman, Kaplan, Pearlman, & Teetzel, 1993) used separate interviews to compare differences in perceptions between patients and physicians. The researchers found that physicians were poor predictors of patients' choices for treatment, and that their predictions were closely linked to their own preferences for treatment. The implication is that physicians' perceptions of patient preference were influenced by their own personal values. One might speculate that nurses' perceptions are similarly influenced.

Two aspects of these studies limit the generalizability of the results to imperiled infants and their families. First, patients in both

studies were adults whose treatment preferences were known. Second, patients in these studies were identified as potential subjects because they had a less than 50% chance for five-year survival. These selection criteria suggest that, unlike imperiled infants in an NICU, patient conditions in these studies were not of an immediately critical nature.

One study specifically examined certain aspects of the decision-making process used to withhold or stop life-support for adult patients. Researchers tape recorded actual discussions about treatment discontinuation among family members, patients, and physicians (Miller, Coe & Hyers, 1992). Analysis of transcripts of these discussions revealed that the focus of discussions was consensus building between participants but that physicians directed the discussions and narrowed options for treatment choices to those consistent with their judgments during decision closure. The researchers acknowledged, however, that decision making to withhold or stop life-support from critically ill patients involved a complex and difficult process that needs further exploration through research.

More disturbing than this are the results of several studies that show that even when patients' wishes are known, physicians tend to make decisions based on their own values (Orentlicher, 1992). In his review of several studies. Orentlicher speculates that there may be many reasons why physicians' values dominate in end-of-life decisions, including an ignorance of patients' preferences, a relative lag in implementing new theoretical approaches to patient autonomy into

practice, a discomfort with conducting discussions with patients to determine preferences, and the belief that patients feel uncomfortable making such decisions and rely on physicians to make them on their behalf. Whatever the reason, clearly physicians must learn to identify their own values regarding treatment options and be able to recognize how their values affect presentation of information to patients and families, and ultimately, the decision they must make.

Although these studies examined situations for adult patients and their surrogates, the findings have implications for health care providers of imperiled infants. If perceptions among patients, their surrogates and physicians are so different, there is a need to improve communication among these decision makers. Physicians must distinguish their personal choices for treatment from their professional opinions about available options and offer more information about available treatment options to surrogate decision makers. More importantly, physicians must solicit information about treatment preferences from surrogates and be open about their own preferences.

The role of the nurse was not discussed in these studies. Nor was there much discussion about what impact a non-collaborative decision making model had on families. The benefit to families from a collaborative decision making process lies in the potential for better understanding and appreciation for families' preferences. One might suspect that nurses can promote such a collaborative process by

focusing on facilitating communication between physicians and infants' families.

Many professionals (Ellison & Walwork, 1986; Novak, 1988: Rushton, 1990: Steele, 1987) believe that nurses can facilitate communication between families and physicians during ethical decision-making. There is some research evidence to support this belief. Parents and providers in one study (Able-Boone, Dokecki, & Smith, 1989) described nurses as the communication bridge, and identified them as the primary source of information about their infants. These results provide some evidence to indicate that nurses acting in the communication facilitator role have a positive impact on families' experience with the decision-making process to consider W/W treatment from their infants. In addition to the research already described, five pivotal studies provide information relative to families' experience with decision-making.

Pivotal Research

Schlomann and Fister (1995) completed a qualitative study to develop some understanding of how parents of critically ill infants in the NICU perceive their role in decision-making. Participants in this study were parents whose infants were expected to die, but did not. The infants from this study all survived, all with moderate to severe disabilities resulting from their NICU treatment. All the parents pursued aggressive measures to save their infants. What is not clear from the research report are the demographics of families, or whether

or not they were ever approached about W/W treatment from their infants.

According to the researchers (Schlomann & Fister, 1995), these parents felt that having information, without direct involvement, would have been acceptable. In contrast to this, parents did not wish to abdicate their role in decision-making, and expressed a desire to be more involved in making decisions for their infants. When parents described their efforts to obtain information, it was clear that many believed physicians were withholding information about their infants from them. Parents felt limited in their ability to participate in decision making because of their ignorance (need for more information), the limited choices available to them, and concerns over the responsibility for the outcome of treatment decisions.

Results also indicated that these families felt abandoned by staff, which Schlomann and Fister (1995) attributed to the emotional distance of the staff, giving parents the impression that the staff were uncaring. Many families did identify the tendency of caregivers to go too far in their efforts to save babies without providing support for follow-up, yet these families did not identify themselves with this phenomenon.

In a research study investigating parental grieving following the decision to withdraw life-support from an infant in the NICU, researchers used open-ended interviews to assess parents' psycho-social status and recall of events surrounding the death of their infants

(Walwork & Ellison, 1985). Parents in the study had participated in the decision-making process to withdraw life-support from their infants, and their infants died following withdrawal of life-support. Interviews were conducted at least one year following the death of the infants. Results from the study contradict physicians' assumptions that parents will suffer adverse reactions after participating in the decision-making process.

The researchers (Walwork & Ellison, 1985) found that participation in the decision-making process had no significant impact on parental grieving or feelings of guilt associated with making the decision. Parents in this study also felt information shared in the decision-making process was clear and understandable. What is not clear from this study is how the parents perceived the process to resolve the dilemma about treatment options, or what information was shared between physicians and parents. It also must be noted that most of the participants were white, middle-class, and had at least a high school education. According to the researchers, parents who were members of minority groups, were poorly educated and had low socio-economic status tended not to elect to withdraw treatment from their infant, which eliminated them as potential subjects for the stud. They identified strong religious convictions as one possible explanation for this tendency.

Two studies, one a pilot (Pinch, 1990) and the other a longitudinal study with three phases (Pinch & Spielman, 19961 Pinch

& Spielman, 1993; Pinch & Spielman, 1990), used a semi-structured guide to interview parent informants about their experience with general ethical decision-making in the NICU. Parents were asked to describe times during their infant's stay in the NICU when they were unsure of what was the correct thing to do. In the pilot study, Pinch (1990) found that parents perceived themselves as passive observers in the decision-making process in the NICU. Participants in the pilot were purposely selected to provide a wide variety of patient conditions and to test the feasibility of the interview schedule. Interviews took place anywhere from immediately following an infant's discharge from the NICU, up to three years after discharge.

In phase one of the longitudinal study (Pinch & Spielman, 1990), findings from the pilot study were confirmed using similar methodology with a non purposive sample. Parent informants were interviewed prior to their infants' discharge from the hospital. As in the pilot study, informants were asked to reflect on a time when they were unsure of what was the right thing to do while their infants were in the NICU. The results from phase one found that parents do not perceive themselves as having an active role in decision-making in the NICU (Pinch & Spielman). Parents described a medicalization of the decision-making process as the reason for their limited involvement.

In phase two of the longitudinal study (Pinch & Spielman, 1993), parent informants were interviewed six months following the discharge of their infants from the NICU. Parents were asked to reflect

back on their experience and probed specifically for perceptions about ethical dilemmas described in the literature. Findings were that between the time of discharge and the interview, parents developed an awareness of the ethical nature of decisions that were made while their infants were in the NICU. This developing awareness led them to search for meaning in their experience. This search included contemplation about decisions that were made for their infants in the NICU.

In phase three of the longitudinal study, parent informants were interviewed four years after the discharge of their infants from the NICU. Again, parents were asked to reflect back on their experience, with particular attention to times when they felt they were unsure of what was the right thing to do (Pinch & Spielman, 1996). Parents reported that while their infants were in the NICU, they needed, but did not receive frequent, repetitious information in simple language they could understand. In addition, parents continued to describe how uninvolved they felt in ethical decision-making in the NICU.

Following completion of data analysis for this study, Kirschbaum (1996) reported findings from a phenomenological study that explored what meanings parents found in deliberating the use of life-support treatments for their children. Participants in this study were parents who had made a decision to forgo or withdraw life-support from their infants or children in the NICU or pediatric intensive care unit. Findings revealed that parents' sense of self as

parents was central to the meanings they found in the experience of participating in ethical decision-making for their children. Parents identified key values and factors that had a significant impact on their decision. Ultimately, these factors helped them frame their decision in terms of their responsibility and obligations to their children.

Findings from all these studies reveal significant information only about parents' perceptions of general and life-support ethical decision-making. There is some data about what information parents found helpful in making ethical decisions. However, there is less information about specific communication between parents and health care providers, or the process used to discuss the ethical decisions.

While individual stories of parents' experience in the NICU are compelling, the power of their meaning is diminished when they are told separately. Strictly quantitative research methods are not useful for exploring the rich information found in these stories. Qualitative research methods offer the best opportunity for drawing links between the similarities and highlighting the differences in the central themes of these powerful stories. Qualitative methods magnify and bring into focus the compelling power of individual stories by providing a disciplined review of the content of several stories. This research used qualitative research methods to illuminate the central themes of parents' stories and to bring into focus critical aspects of their experience with the ethical decision-making process used to consider W/W treatment from their infants in the NICU.

This research builds on the findings of Schlomann and Fister (1995), Walwork and Ellison (1985), Pinch (1990) and Pinch and Spielman (1990, 1993, 1996). Like the Kirschbaum (1996) study, this research is more focused than the previously cited studies. Elements of each of these study designs, including interview type, length and timing in relation to the death of an imperiled infant, were used to create the design for this research. This research sought to extend the findings of these earlier studies by using similar methods to focus on a specific aspect of parents' experience in the NICU. It used a semi-structured guide to interview parents specifically about ethical decision-making as it relates to the process used to consider W/W treatment from an imperiled infant. This study also included parents whose infants died, whether or not the parents consented to W/W treatment from their infants.

The core of this research is descriptive in nature and utilized qualitative methods to explore parents' experience with the decision-making process used to consider W/W treatment from their infants in the NICU. Data analysis used phenomenological and content analysis techniques to achieve an approach that is a blending of qualitative and quantitative methods. As a descriptive study, there is no rigid a priori framework from which to work as there would be in a hypothesis-testing design. It is important, however, to articulate the paradigmatic perspective used to approach this area of study and some underlying assumptions central to the development of research questions.

Theoretical Framework

Nature of the Paradigm

This research design rests on a constructivist paradigm. This paradigm supports naturalistic forms of inquiry and views the reality to be investigated as relative, meaning that there can be multiple realities, each of which is determined by an individual's experience. Truth in this paradigm is subjective and dependent on transactions between individuals and their perceptions of experiences (Denzin & Lincoln, 1994; Guba & Lincoln, 1994). Truth in this sense is contained in each individual's experiences. This research explored parents' experiences as an indication of their reality. The research interview stimulated parents to articulate the content of their truth by encouraging them to put their experience in to words and give it meaning. The truth of their experience is given in their perceptions of reality. Embedded within the constructivist paradigm, and relevant to this research, are some assumptions and beliefs about family and ethics.

Family Theory

How family is defined depends in part on the theoretical perspective of the person creating the definition. While family may be defined in a number of different ways, for the purpose of this research family of an infant is restricted to the parents of an imperiled infant because they are largely responsible for the care and future of the infant and they are the individuals whom physicians must consult when

considering W/W treatment. The entire family unit includes the infant and parents.

The underlying assumption of this research is that the family (parents of an imperiled infant and the infant) is a unit that interacts with others (health care providers) in an environment (the NICU) in response to events (the crisis of considering W/W treatment from their infant). This view of the family is consistent with a systems theory approach to studying families (Friedman, 1992; Whall, 1991). Central to this concept of the family is the idea that members of the family, the parents in particular, are struggling to adapt to the new structure of their family unit, namely, the addition of a new infant. This adaptation may be hindered by the crisis of an ethical dilemma

Ethical Theory

In the event that a person is incapable of making decisions about his or her medical care, which is certainly the case with infants, someone must act as a surrogate decision maker. Surrogate decision makers may use an advance directive, substituted judgment, or the principle of best-interest for guidance in resolving an ethical dilemma (Buchanan & Brock, 1989). Advance directives require prior legal verification of a person's wishes for treatment options. Substituted judgment requires at least prior knowledge of a person's wishes for treatment. Neither of these approaches is possible with infants.

The best-interest principle is the most widely used standard for surrogate decisions regarding infants because infants clearly cannot

provide advance directives, nor have they any life experiences or values on which to build a substituted judgment (Arras, 1987; Buchanan & Brock, 1989; Fost, 1981). Parents are not true surrogates in that their decisions are not made in place of the decision the infant would make for itself. Parents make decisions on behalf of their infant, not in place of their infant. In the ethical decision-making process of considering W/W treatment from imperiled infants, it is assumed that parents consider treatment options from the perspective of the infants' best interest, based on their own personal values, while health care providers use their clinical expertise, which is also influenced by their personal values, to recommend treatment options consistent with the infants' best interest.

Regardless of what is used for guidance, making decisions about life-support for imperiled infants often poses an ethical dilemma. An ethical dilemma arises when two or more clear principles could apply to a situation, but each supports mutually exclusive courses of action to resolve the dilemma (Beauchamp & Childress, 1989). While an option may be consistent with a particular perspective, choosing one over the other has consequences because all options offer solutions that pose both benefits and harms, and in most cases are mutually exclusive. In the case of ethics, a clash of moral values centering on which principle to apply or a competing of ideals often leads to conflict. The presence of conflict characterizes a dilemma.

Conflict manifests when decision makers differ on how they assign priorities or interpret roles and responsibilities (Broom, 1991) or when they value the available options for resolution differently. Conflict may be internal to an individual or between individuals. While some ethical dilemmas are rooted in conflicts between basic ethical principles and how those principles should be valued, most are rooted in misunderstandings of what is at issue. Frequent sources of conflict include different perceptions of what is the central issue, what will be the consequences of different alternatives, values, feelings of responsibility, motivations, incompatible goals and competition for resources between individuals.

Misunderstandings of what is at issue may stem from different ways of knowing (Anspach, 1989). Ways of knowing refers to how experiences lead people to identify and value facts necessary to consider in discussions involving W/W treatment from infants. Even in cases where decision makers agree on the ethical principles at issue, they may not be able to agree on the prognosis of the infant (Anspach). In cases where prognostic ambiguity is due to a lack of objective knowledge, physicians, nurses and parents, because of their different experiences with the infant, may have different methods for making prognostic assessments. Even if all the participants in an infants' care use best interest as a guide for making a decision, each of these individuals defines best interest from their own reality which is defined by their individual experiences with the infant. Providers may

impose their meaning on the situation, particularly if they have not explored parents' experiences.

Parents and nurses respond to events in the NICU by focusing on the infant's best interest and quality of life, and how those interests affect the family of the infant and society as a whole. Their perspective rises from relational reasoning. This approach is consistent with what Duff (1987) calls 'close-up' ethics. Close-up ethics acknowledges the importance of individuals and feelings as well as ethical principles. It requires active participation of parents and health care professionals. Because it is founded on the ability to appreciate and understand abstract ethical principles and empathy, practicing close-up ethics is difficult (Duff). This perspective has been described as an ethic of care by Gilligan (1982).

Physicians, on the other hand, tend to focus more on technology to solve problems. This perspective is consistent with linear rational thinking. This approach is what Duff (1987) calls, 'distant' ethics, since it relies on abstract principles. Distant ethics is easier to practice because it relies on rules derived from scientific, philosophical, or legal analysis (Duff, 1987). This perspective has been described by Kohlberg (1981) as a system of ethics based on justice.

The central problem with labeling these two perspectives as relational and rational is the false impression these labels create and the misconceptions they perpetuate. *Relational* seems to imply a highly emotional and unreasonable approach to resolving problems.

Rational seems to imply a systematic and carefully reasoned approach. Both approaches are reasoned and neither is superior to the other. A relational perspective requires lateral thinking on multiple levels, while a rational perspective requires clearly linked thinking, with each step controlled by a rule or principle.

Constructive resolution to conflict in ethical decision making depends on four things. First, participants must learn to identify their own values and perceptions regarding an ethical dilemma. Second, they must learn to acknowledge and respect other points of view as different, not better or worse than their own. Third, they must be able to articulate these differences and discuss them openly. Finally, participants must be able to actively engage in a dialogue about different points of view with the goal of collaborating together to arrive at a consensus decision.

Investigating the meaning parents give to health care providers' words and actions during the decision-making process may demonstrate the necessity for effective communication between health care providers and families. It also will provide material from which nurses will gain insight about parents' perceptions of the process. This in turn will enable nurses to promote the positive aspects of this process. Understanding parents' perceptions of this process will help nurses improve parents' ability to fulfill their ethical obligations to their infants during this difficult time. Nurses will appreciate the

potential for their critical role in initiating and maintaining a collaborative dialogue between decision makers.

In situations where W/W treatment is being considered for imperiled infants, several authors favor parents as the final decision makers for their infants, provided their decision is not in conflict with the prevailing medical opinion (Asch, Cohen, Edgar & Weisbard, 1987; Duff, 1981; Fost, 1981). This view is supported in law and tradition (Fost, 1986). Some would argue in favor of parents participating in but not being responsible for making the final decision (Carr, 1989). Most agree that some degree of collaboration between health care providers and parents is essential for satisfactory resolution of an ethical dilemma that centers around the best interests of imperiled infants.

Although parents are emotional, they are able to participate in making decisions and cope better if they are involved (Schlomann, 1992) and in general, suffer no adverse effects from participation in the discussion to W/W treatment from their infants, even when asked specifically about guilt associated with making the decision (Walwork & Ellison, 1985). The research by Pinch and Spielman (1990, 1993, 1996). explores what parents in the NICU experience with general decision-making, but the results offer no suggestions for determining the nature and extent of parent participation in the decision-making process relevant to W/W treatment from infants. The recent research by Kirschbaum (1996) provides some information about parents' experience in this process.

Summary

A major goal of nursing care for imperiled infants is to facilitate the process of re-establishing the family to include the infant. The process depends to a large extent on the infants' caregivers' ability to transition into their role as parents. Parents' ability to meet their ethical obligations to their infants defines a central piece of the parental role. Better understanding about what families in the NICU experience when they face the ethical dilemma of W/W treatment from their imperiled infants will help nurses support families as they adapt to their new family unit.

This research rests on the underlying assumption that information exchange and communication have a significant impact on parents' efforts to carry out their ethical duties as parents of their seriously imperiled infants. It is assumed that better understanding promotes information exchange, improves communication, decreases potential conflict, and eventually will help in defining the role of nurses in the ethical decision-making process. A more clearly defined role for nurses in the process will lead to the development of nursing intervention strategies that will facilitate a family's ability to adapt to becoming a family during the process of ethical decision-making in the NICU.

This research lays the groundwork for future research that will lead to the development of practice generalizations for ethical dilemmas in neonatal nursing care which could be applied to other

clinical settings. Central to families' experience of an ethical dilemma in the NICU is the process used to make a decision about limiting treatment options for their infants. One way to break down the crucial elements of this decision making process is to examine who was involved in the decision, what information was relevant to reaching a decision, and what meaning participants gave to the experience of participating in discussions to reach a decision. These elements of the decision making process guided the development of the specific aim of this research.

The aim of this dissertation was to answer these questions: 1) How did parents feel about their level of involvement in the decision-making process ? 2) What information was important to parents in reaching a decision about W/W treatment from their infants? 3) What meaning did parents give to comments, advice, and behaviors of health care providers involved in the process? The answers to these questions should reveal crucial information about parents' perceptions of the decision making process.

Chapter 3: Methods

The central purpose of this dissertation was to explore parents' perceptions of the decision-making process when they experienced the crisis of deciding whether or not to W/W treatment from their infants in the NICU. The long-term goal of the project is to improve health care providers' understanding of parents' experiences during this difficult time. Information gained from findings of this dissertation will sensitize health care providers' understanding of families' experiences with this process and help them prepare parents to cope with the crisis of an ethical decision. This researcher utilized a method that blended the strengths of a phenomenological perspective with the strengths of some of the data analysis techniques used in content analysis, to collect and analyze data for this dissertation.

Methodological Framework

A phenomenological perspective that uses open-ended interviews to collect descriptive data was chosen for three reasons. First, it is reasonable to assume that participants in the decision-making process employ different tactics for reaching resolution of the ethical dilemma. Second, one of the greatest strengths of phenomenology as a method is that it allows informants to discover and relate the meaning of their experiences by allowing them to tell their stories in their own words. Third, research methods that allow individuals to articulate their own perceptions of the experience

provide the richest, most informative data for analysis of the decision-making process.

One of the greatest strengths of content analysis is that it allows the researcher to use his or her own experience with certain phenomena to guide collection and analysis of data. The underlying assumption of the central research question for this study was that communication and information exchange between parents and health care providers has an impact on the experience of families. The content of communication served as a basis for drawing inferences about the researcher's assumptions.

Content analysis techniques blended with the phenomenological perspective allowed the researcher to focus her expertise with W/W treatment discussions in the NICU on what was significant to parents' experience with this dilemma. The phenomenological approach allowed parents to reveal what they found significant in their experience and forced the researcher to confront personal biases regarding what was important. The content analysis approach helped the researcher use expertise to focus the analysis on the pieces of parents' stories that were relevant to the study aims.

Informants

Selection Criteria

Informants for this study were parents whose infants were admitted to and received treatment in the NICU and ultimately died following consideration of W/W treatment. Parents, regardless of

their decision to accept or decline W/W treatment from their infants, must have participated in discussions to consider W/W treatment while their infants were still in the NICU. Parents were included regardless of their decision because limiting the sample to only those who agreed to withdraw treatment might have skewed the sample in favor of white, middle-class, well-educated informants and against minority and poorly educated informants (Walwork & Ellison, 1985).

Informants were identified by reviewing NICU records for infant deaths from the NICU in a large metropolitan hospital. NICU records were reviewed to identify infants whose deaths occurred after their parents participated with health care providers in discussions to consider W/W of treatment. While ethicists make no distinction between the moral reasons that support withdrawing versus withholding treatment, health care providers (and presumably parents) distinguish the two on the basis of the perceived locus of moral responsibility for the patient's death (Slomka, 1992). Withdrawing treatment requires an action which makes it an active. Withholding treatment is passive because it requires inaction.

For the purposes of this study, withdrawal of treatment was defined as any active termination of treatment that an infant was already receiving. The most common example was withdrawal of the ventilator from an infant who relied on it for effective support of respiration. Withholding treatment was defined as limiting the extent of treatment options offered to an infant. An example of this was a "do

not resuscitate" order restricting administration of cardio-pulmonary resuscitation in the event an infant's heart stopped.

There were only three criteria for inclusion as informants in this study. Parent informants must have participated with health care providers in a discussion to consider W/W treatment from their infants in the NICU, their infants must have been admitted to and received treatment in the NICU, and their infants must have died. The only exclusion criteria for parent informants was a refusal to participate and/or an inability to comprehend and speak English. Fluency in English was determined through reports from health care providers and from references to the use of interpreters in the infant's record.

Informants were not excluded from the study if only one parent wished to participate. There were two reasons for this. First, there may have been only one parent involved in the decision-making process. Second, since fathers and mothers differ in their progression through and expression of the grief process (Kissane & Bloch, 1994: Affleck & Tennen, 1991), it was expected that in some cases, the mother and father of the same infant would differ on their willingness and ability to talk to the researcher about their experience. The researcher felt that hearing even one parent's perspective on the experience would provide valuable information about the family's experience.

Informant Recruitment

Potential informants, identified by the primary investigator through NICU record and infant chart reviews, were contacted initially by a nurse who practiced in the NICU but did not provide direct patient care to their infants. Initial contact by this neonatal nurse was a telephone call to potential informant's homes. The telephone contact consisted of an explanation of the research study and an invitation to participate. In cases where telephone contact was not possible, potential informants were sent a letter explaining the study and a postage-paid post card that they could return to the primary investigator if they wished to participate.

Experts in the grief literature continue to debate the amount of time necessary for individuals to recover from the irrevocable loss imposed by the death of a loved one. It is believed that after a relatively brief period of time, the individual will achieve a state of recovery and return to normal functioning. The length of this brief period of time depends on many factors, including the suddenness of the loss and the trauma involved (Wortman & Silver, 1989).

Initial contact with informants in this study occurred no sooner than three but not later than eleven months after their infants' death. The rationale behind this time-line was to provide enough time for the parents to overcome the initial stages of grieving over the loss of the infant but not so long that their memories of having participated in the decision-making process had faded. Interviews with informants were completed no later than 12 months from the death of their infants.

Within one week of the initial contact by a neutral person, the researcher sent interested parents a letter about the study.

The investigator's letter briefly described the study, its purpose and the methods used to collect data. One week following the mailing of the letter, the researcher contacted the families by telephone to obtain initial consent to participate, clarify information about the study, and answer any questions. If consent was granted, a consent form was mailed to informants in advance of the scheduled interview and arrangements were made for an interview to take place. Reasons for declining to participate varied, but usually related to where parents were in their grief work.

Informants were offered the choice of being interviewed in their home, at the hospital where their infants died or in a neutral location. Interested parents who lived greater than 30 miles from the hospital where their infants received treatment were given the option of participating in a telephone interview. Informants who chose to participate in telephone interviews were sent a letter confirming the agreed upon time and date for the interview. They also received a copy of the written consent form with a postage-paid envelope for return of the signed version to the researcher prior to the interview.

Procedures

Data Collection

Prior to data collection and approval from the Institutional Review Board (IRB), the researcher contacted the nursing and medical

directors of the NICU. The researcher discussed the project with the nursing and medical directors to enlist their support. These directors each wrote a letter of support for the project. Both letters were included with the information submitted by the researcher to the IRB. Once approval for the project was granted by the IRB, the researcher identified a recruiter to contact potential informants. In cases in which both parents consented to participate, they were interviewed together. It was assumed that they were together during the decision-making process.

Meanings and stories elicited from interviews are context dependent, and informants respond to the interviewer as well as other informants participating in the interview (Mishler, 1986). The challenge to the researcher is to be ever watchful of his or her influence on the informant. The researcher must remain neutral and encourage informants to tell their stories as they want to tell them, not as they think the researcher wants to hear them. As a way of combating interviewer effects, this researcher felt it necessary to conduct pilot interviews and have the interviewer's skills evaluated by a mental health expert for quality of interactions with informants. Feedback from the mental health professional regarding the researcher's pace of speech, clarity in asking questions, use of silence and ability to encourage the interviewee to relate their experience in their own words was used to improve the researcher's skills as an interviewer.

Interviewing style and technique of the researcher were developed using evaluations by the mental health professional and suggestions found in Mishler (1986) and Merton, Fiske, and Kendall (1990). In addition, with each interview, the interviewer noted her own affect and reactions to information shared, who participated, how the make-up of informants differed, if at all, from that in the described decision-making process and, how interviews of individual parents may have differed from those that included two informants.

Informants who chose to participate in a telephone interview were asked to confirm their written consent to participate, sent to the researcher, by verbally acknowledging a summary verbal consent. When informants and the researcher met for face-to-face interviews, the researcher confirmed the informants' consent to participate, asked each one to sign the consent form, and then proceeded with the interview. The logistics of conducting interviews and the sensitive nature of the interview prohibited the presence of a neutral person to witness the signing of the consent form.

In qualitative research, sample size is not predetermined, because it depends on the nature and richness of the data and where data analysis leads the researcher (Sandelowski, 1986). Researchers must obtain enough data from interviews to represent the phenomena under study, but be careful not to be inundated by redundant or irrelevant data. To achieve this goal, this researcher conducted 17 focused interviews. Five of the total interviews served as pilots for the

study. Twelve interviews were used in data analysis. The decision to close data collection was made in consultation with members of the research committee once the researcher determined she had reached phenomenal saturation as described by Sandelowski (1995a).

The interview consisted of five open-ended questions (see Appendix A). The structure of the interview allowed for a question to build rapport to begin the interview. The three central questions each focused on one aim of the research, namely parents' involvement, the information they found helpful in the process and the meaning they found in providers' comments advice and behavior. The final question provided the informant with an opportunity to share any concerns about any aspect of their experience with the researcher and thus provide a bridge to closure to the interview experience.

The selection of questions and prompts was guided by information from relevant literature, the general research question for the research, and the identified specific aims of the research. Since the focus of this study was to examine perceptions of informants, the questions were framed in such a way as to elicit depth and personal context of the informants' experiences (Mishler, 1986). However, the wording of each of the questions varied slightly to maintain consistency with the vocabulary an informant used to respond to each question.

Focused interviews limit the scope of information but can provide informants the opportunity to tell their stories. The first and

last questions of the interview were generated with the goals of phenomenological research in mind. They were designed to be as open as possible to allow participants the chance to articulate their perspective of the phenomenon under study (Mishler, 1986). The middle three questions were generated so that each one addressed a specific aim of the research, namely involvement, information, and meaning. The focused nature of these questions reflected the influence of content analysis on the creation of the methods for this research. The interview lasted anywhere from 35 minutes to 1 and 1/2 hours. The average length was 45 minutes.

All interviews were audio tape recorded and transcribed verbatim. Immediately after the interview, the researcher took notes relevant to the affect of subjects, nonverbal behaviors, the atmosphere where the interview took place, and her impressions of the interview process. Informants were identified in the transcripts by code only. The researcher had the only key that linked informants' identities with data.

In addition to interviews, informants were asked to supply demographic information following the interview. Parent Information: age, sex, marital status (presence or absence of significant other), ethnic origin, religiosity, education level, obstetrical history (previous births, pregnancies, perinatal loss), elapsed time since infant's death at the time of the interview, and payment method. Infant Information: gestational age (as indication of prematurity), birth

weight, resuscitation efforts (at birth and during hospitalization), diagnosis, prognosis, surgeries, treatments, procedures, age when discussion with parents about W/W treatment took place, and age at time of death.

<u>Protection of Informants</u>

The benefits to the informants of participation in qualitative research interviews are linked closely to the harms and relate to the opportunity to talk about the phenomenon under investigation. Risks of participating in interviews include developing an intense relationship with the interviewer with the expectation that therapeutic interventions will result, a subjective interpretation of information by the interviewer which is inconsistent with the informant's interpretation, and adverse responses from either the informant or the interviewer to sensitive and emotional issues discussed in the interview (Ramos, 1989; Cowles, 1988). Benefits of participating in interviews include catharsis, which can lead to feelings of relief; self-acknowledgment and confirmed feelings of self-worth; a sense of purpose through helping others, self-awareness, which may contribute to gaining a new perspective; and empowerment, which contributes to healing (Hutchinson, Wilson & Skodol Wilson, 1994).

The two major areas of risk to informants in qualitative research include possible exposure (breach of confidentiality) and self-exposure (internal self-evaluation) (Larosso, Bennett, & Gelles 1981), which may also be considered a benefit. Informants in this study faced greater

harm from self-exposure. Parents who have experienced the death of their infant following discussions about W/W treatment have powerful memories associated with the experience and suffer from some degree of grief. Talking about the experience had the potential for bringing up painful memories for parents, but parents also may have been more inclined to remember their experience as more positive because they have a tendency to compare themselves with others in worse circumstances (Affleck & Tennen, 1991). Informants in this study were provided with a list of community resources such as grief support groups and mental health services.

Data Analysis

Data Analysis Procedures

Although qualitative methods tend to be non-numeric, even staunch practitioners of qualitative research rely on an underlying logic of quantification in their efforts to organize and analyze data (Morgan, 1993). There is support for a move away from following traditional analysis techniques in favor of establishing analysis techniques that match the purpose of the research (Morgan). With this goal in mind, this researcher chose to combine principles from phenomenology with techniques used in qualitative content analysis to create a blended method that is consistent with the goals of this study.

A phenomenological qualitative content analysis approach (PQCA) is an appropriate choice when, as is the case for this study, the goal of the research is to generate understanding of another's

perspective by describing lived experience. Table 1 summarizes the procedures used in the analysis process for this research. The steps in the process were developed using suggestions from Sandelowski (1995b) and adapting a phenomenological analysis procedure described by Streubert (1991). PQCA seeks to establish a middle ground between the extremes of quantitative content analysis and qualitative phenomenology.

Table 1

Steps Used in the Analysis Process

1. Transcribe each interview.
2. Write a summary abstract of each individual interview.
3. Extract the relevant facts to create an event history.
4. Develop a story line and topics using study aims.
5. Review each transcript for significant themes.
6. Determine relevance of themes to study aims.
7. Develop codes and definitions for themes.
8. Establish intra-rater agreement
9. Establish inter-rater agreement.
10. Using transcripts, refine codes and definitions.

Focusing the analysis process for PQCA depends heavily on successfully completing the first six steps. Summarizing the interview in a story format provides the necessary foundation that enables the researcher to appreciate the context of the themes, and their relevance to the study aims. PQCA uses preestablished code categories based on the study aims to support the process of refining codes that emerge from the data. Preestablished codes were essential because they allowed the researcher to focus on the significance and relevance of themes, in relation to the study aims. Data analysis is complete only after the final six steps of the process have been repeated and the researcher can articulate and defend the significance and relevance of identified themes.

Themes are, at best, simplifications of any experience. Codes are a representation of the emerging themes. The theme serves as a way of capturing the meaning of the phenomenon one is trying to understand (VanManen, 1990). In determining the essential quality of a theme, the aim is to discover properties that define a phenomenon. Without these essential properties, the phenomenon could not be what it is. Themes are a representation of these properties. One must answer the question: Is the phenomenon still the same if we imaginatively change or delete this theme (VanManen)?

In this research, data were generated through interview transcripts and interviewer notes about the process. Counting the frequency with which codes appeared within and between interview

transcripts revealed patterns that guided further interpretation of the data. In addition to the frequency with which codes were applied, the intensity of the information to support the codes guided data interpretation. Intensity of information was evident in listening to tapes of the interviews and reviewing notes about the interviews. PQCA places emphasis on understanding the context of themes that are revealed by the coding and counting process, and appreciating the meaning of these themes.

Data analysis began after the first interview. With the study aims as a guide, codes were established through consultation with members of the dissertation committee. The researcher continued to conduct interviews simultaneously as codes were refined. As is true with most qualitative research, new codes evolved as themes emerged from conducting more interviews and analyzing transcripts. Once the categories and codes became more consistent, the researcher established rules for coding.

Prior to establishing inter-rater agreement, the researcher established intra-rater reliability by returning to transcripts for coding at least twice, with a two-week time interval, to compare agreement between coding experiences. The purpose in achieving intra-rater reliability was to clearly establish the researcher's interpretations of text over time. Seeking inter-rater agreement served as a way of preventing the researcher from misinterpreting text, or overlooking significant themes as a result of her own biases.

Inter-rater agreement was established with the help of two other qualitative researchers. The researcher provided each coder with a complete set of instructions and coding sheets which included definitions for each code. Each qualitative researcher was asked to use the coding sheets to independently code two interviews. Inter-rater agreement was established by comparing this researcher's coding results with those of the two volunteer coders. Once reliability was assured, the researcher coded the remainder of the interviews.

Following completion of data collection, descriptions of the results were reviewed by a clinical expert in neonatal nursing to verify the credibility and fittingness of the results. Informant responses were compared with the collected demographic data to identify any striking similarities or differences among informants' responses that could be attributable to demographic characteristics. None were noted.

Rigor in Qualitative Research

The four criteria for rigor in any research are its truth value (creditability), applicability (fittingness), consistency (auditability), and neutrality (confirmability) (Sandelowski, 1986)). In PQCA, credibility does not depend on determining the one absolute truth, because the underlying paradigm does not recognize one truth. The critical issue is whether or not the researcher's interpretation is realistic and plausible when compared with potentially plausible alternative interpretations (Mishler, 1986). Creditability is achieved when phenomena become meaningful through an informant's perceptions (Sandelowski, 1986).

Fittingness is determined by the ability of the researcher to keep informants' stories and the representativeness of informants' experiences of the phenomenon under study in their proper perspective. Evaluating fittingness can be achieved in part by having independent researchers validate the findings (Sandelowski).

The data-collection strategies and analysis techniques for this research were chosen to ensure rigor and to optimize the auditability, and ultimately the replicability of the decision trail. In addition, concern for informants' confidentiality and potential emotional distress guided the data-collection strategies. Confirmability and fittingness were achieved through the independent evaluation of results by expert qualitative researchers and an expert in neonatal nursing. Members of the dissertation committee evaluated auditability by reviewing the steps in the analysis process and reviewing the researcher's decision trail as analysis progressed.

During the course of each interview, the researcher used reflective questions to elicit informants' feelings about the researcher's interpretations of their comments as a way of achieving some level of credibility. In addition, informants were given the opportunity to verify codes and their interpretations via pre-paid post cards sent to them by the researcher. The researcher sent abbreviated copies of the results and discussion sections of the research to each informant. Two families responded (three informants) and affirmed the investigator's interpretations of their experience.

The rigor of any qualitative research project determines its degree of excellence. Achieving sufficient rigor depends on whether or not the methods chosen satisfactorily address creditability, fittingness, auditability, and confirmability. PQCA is consistent with the goals of this research project and adequately addresses each of the four criteria for rigor.

Chapter 4: Results

Findings from this study yield information that will help providers better understand what families in the NICU experience when they face the ethical dilemma of considering whether or not to W/W treatment from their critically ill infants. Findings are presented with the goal of improving health care providers' understanding of parents' experiences during this difficult time. Findings reveal key aspects of parents' perceptions of the discussions central to the decision-making process concerning W/W treatment from their infants. Such an experience for parents can never be good, but the results of this research indicate that there are things providers can do to make it more positive by promoting parents' abilities to fulfill their ethical obligations to their infants in this painful circumstance.

Data Generation

Data for this study were generated over an eight-month period. Interviews were conducted both in person and by telephone. It is possible that the interviewer interaction situations (in person or over the telephone) had some influence on the data. However, no significant differences in richness of data were found between in-person and telephone interviews. Five families participated in pilot interviews. These interviews were used to refine the interviewer's skills and the interview questions. Following these pilot interviews, twelve focused interviews yielded over 300 pages of transcript text. In

addition, data analysis and the researcher's theoretical as well as procedural notes yielded over 100 pages of text.

Themes were the identified unit of coding, while the interview question served as the unit of context for data analysis. Codes are labels used to identify emerging themes. (See Appendix B for coding sheets, including instructions given to other raters and a code counting sheet. Formulating a thematic understanding of data is not entirely a rule-bound process (VanManen, 1990). The frequency with which a theme appeared both within single interviews and among all interviews in part determined its significance. In addition, the intensity of the informants' description and the impact on the overall experience defined a theme's significance.

For example, the code "need for information" evolved because participants often described their desire to receive information about their infants' medical condition, prognosis, comfort, and treatment plans. All participants related some comments that fit this description. Some participants repeated descriptions of seeking information several times during the course of the interview, regardless of the question being asked by the interviewer. Some spoke with great intensity and at great length about their need for information. In addition, for more than one family, meeting this need, or failing to, had a dramatic impact on their overall experience in the NICU. For these reasons, this code was developed to identify a significant theme in participants' stories.

Parents and their experience with discussions to consider limiting treatment options for their infants are unique. However, in many ways, what was important to different parents was similar. Each informant's story revealed a piece of the puzzle about the overall experience for all informants. For example, one story highlighted critical aspects of involvement while another highlighted crucial aspects relevant to information. Particular elements of the overall experience were emphasized in individual cases. Examining highlights together contributed to understanding the essence of the overall experience for all informants.

The researcher attempted to identify themes that had relevance for many families, themes that were generalizable between families. In some cases, an individual's story revealed a powerful theme; however, if that theme could not be found in others' stories, for the purpose of reporting findings it was not considered significant for this study. Contemplating nontextual but contextual elements, such as informants' tone of voice, affect, and intensity of speech, also contributed to determining theme significance. Knowledge about the nontextual elements was gained through living in the data.

Living in the data consisted of actually doing the interviews, reviewing notes the researcher recorded immediately after interviews, reviewing interview tapes, undertaking multiple readings of the transcripts, writing extensive notes about the analysis process, and writing iterations of the data analysis. Some contextual factors that

contributed to determinations of significance included who participated in the interview, the length of the interview, and the enthusiasm expressed for participating in the interview. Significance of themes also was determined by noting the presence or absence of factors mentioned by families in the context of their overall experience, identified as being positive or negative.

Informants

The researcher reviewed charts for every infant who died after receiving treatment in the NICU. The chart for each infant who died during a 16-month period was reviewed to determine if the parents were eligible to participate. Table 2 summarizes information relevant to the available pool of potential informants for the study. All of the study informants were married and living with their spouses; however, in some cases, only one spouse participated in the interview. Informants ranged in age from 19 to 40 years and were a combination of first-time parents and parents with other living children. The majority of informants were white, had at least some college education, had health insurance, and stated they were moderately to very religious. The demographics of informants for this study were expected, given the small sample size, the English-speaking criterion required for participation, and the demographics of the regional population where the data were collected.

Table 2

Statistics from NICU (August 94-December 95)

	number
total deaths	44
total families *	41
sudden deaths	8
W/W treatment	36
language barrier +	4
eligible families ~	31
unable to locate	8 (26 %)
declined to participate ^	5 (23 %)
interviews completed	17
pilot interviews	5
interviews for analysis	12

*   Two sets of twins, one set of siblings born 11 months apart
      (family ineligible because of language barrier).

+   Four infants were eliminated because of language, three
            families.

~   One family was not recruited because data collection closed.

^   1. "It's over, in the past."
      2. "I have my hands full with her twin."
      3. After agreeing to participate, could not be contact by
      telephone.
      4. Parents were divorcing because of birth and death of infant.
      5. After agreeing to participate, parents reconsidered because of
      emotional distress.

It is probable that informants whom the researcher was not able

to locate would have increased the racial, educational, and religious

diversity of the sample. It is also a reality that some families who

experience the crisis of an NICU admission are not able to

communicate in spoken English without the assistance of a translator, which was a criterion for participation in the study. Three families who met other criteria for participation in this study were not recruited, because of language difficulties. Table 3 summarizes demographic characteristics of informants.

Table 3

Informant Demographic Information

informant Number	Age	Marital Status	Ethnic Origin	Relig- iosity	Edu- cation	Obstetric History	Payment Method
3A	38	M	C	V	G	G1, P0	I
3B	32		C	V	C		
7A	33	M	C	M	HS	G2, P1	I
7B	35		C	M	HS		
9A*	34	M	C	V	C	G2, P1	I
9B	28		C	V	TS		
10A	34	M	C	M	C	G3, P2	I
10B	34		C	M	C		
11A	40	M	H	V	C	G5, P4	S
11B*	34		C	V	HS		
13A	27	M	C	M	D	G2 ,P0	I
13B	25		C	M	G		
14A	40	M	C	V	G	G3, P,2	I
14B	33		C	V	G		
15A*	29	M	C	N	C	G2, P2	I
15B	22		C	N	C		
17A	24	M	C	V	HS	G1, P1	I
17B	22		C	V	C		
6A	38	M	C	M	C	G5, P4+	I
6B	38		C	V	HS	G2, P1	
12A	29	M	C	V	P	G1, P0	I
12B	26		C	M	G		
16A*	19	M	C	M	H	G1, P0	I
16B	20		C	V	HS		

Table 3 Notes: *did not participate in the interview, + children from previous marriage. Marital Status: M = married; Ethnic Origin: C = Caucasian, H = Hispanic; Religiosity: V = V, M = Moderate, N = Not at all; Education: HS = High School, C = Some College, TS = Trade School, G = College Degree, H = did not finish HS, P = Graduate School, D = Graduate Degree; Obstetric History: G = Gravida, P = number of living children; Payment Method: S = Self Pay, I = Insurance.

Table 4

Informant/Infant Characteristics

Interview number	Time in the NICU	Elapsed time since death months	Withdraw (wd) or withhold (wh)	Term/ preterm	Prenatal diagnosis	Reaction to decision making
3	3 days	12	wh	term	no	positive
7	8 days	4	wd	term	no	positive
9	20 days	10	wh*	term	no	negative
10	2 days	5.5	wd	term	yes	positive
11	1 day	12	wd	term	no	positive
13	1 day	7	wd	preterm	yes	positive
14	12 days	7	wh+	term	yes	negative
15	1 day	5	wh	preterm	yes	positive
	1.5 days		wd	preterm		
17	14 days	4	wd	term	no	negative
6	3 mo	6	wh	preterm	no	positive
12	6.5 mo	5	wh	preterm	yes	positive
16	2 mo	4.5	wh/wd	term	no	positive

Table 4 Notes: * baby died at home, parents wanted treatment, + parents declined option to withdraw treatment.

Table 4 summarizes characteristics of the infants whose parents participated in this study. All infants received some initial treatment, which was intended to give each infant his or her best chance, and give providers enough time to assess the infant's needs. Infants lived from 1 day to 6.5 months. Interviews took place between 3 and 12 months following the death of the infant. Half of the infants had treatment withdrawn and half had some form of treatment withheld. Those families who chose to withhold rather than actively withdraw treatment made references to wanting the baby to decide. They were prepared to "pull the plug" if suffering became an issue, and they looked to providers for guidance. They had "no desire to let it [the dying process] drag on." In those cases, babies did not live longer than a week after the decision to withhold treatment.

Some infants were preterm and some were full term. Some families received prenatal diagnoses regarding potentially life-threatening problems. All families, regardless of the nature of their experience (positive or negative), universally mentioned nurses as being instrumental in implementing the decision. Nurses were a central figure and, in all cases, a positive force for supporting families when these infants died.

The majority of participants perceived their experience as positive. Some participants with overall positive experiences identified negative aspects of their experience which related to problems with information exchanged between providers and parents.

Negative experiences were tied to communication problems, not differences in opinion about what was ethically correct.

In two of the three cases where the families' experience was negative, families also experienced conflict with providers about considering W/W treatment. However, this did not appear to be the source of negativity. All three families attributed their negative experience to some problem in communication. Communication problems related to either how information was delivered, both access and presentation, or a lack of coordinated information.

The majority of infants lived less than two weeks. Many of these families described having to make a clear-cut decision about treatment options:

> Yet, I don't remember that that was a difficult decision to make, the decision not to resuscitate her and I think that was primarily because of the fact that you know before... the first thing we knew about her was that she was going to, in all likelihood, live a life in the vegetative state and so, I think that was the biggest part of it, but the other thing was that you know, we also... we hadn't held her and had any time with her. She was just this little baby that was hooked up to machines from the moment she was delivered and so we, I think, we were, I don't know, somewhat, I don't know that detached is the right word... We didn't really have a decision to make. It was just to know this was the situation and that when we did make the decision not to resuscitate her, again, that was very

natural and that there was this little baby, with a thousand wires hooked into her and you know, that didn't seem right thing to do and so,...

While families whose infants lived longer than two weeks described a less well defined decision:

...for the first probably four months, even though they were saying he was very sick on the inside, he looked fine on the outside, you know. So, he looked fine and he interacted with us and he played and he smiled and he didn't seem to be in distress. So it was easier making some of those decisions [various treatment choices]... I mean, there wasn't ... there wasn't really to us a choice not to try, because he seemed to be okay and he felt okay. I mean he was you know, willing to fight and so we went along with that, but from towards the end when we started to see him more uncomfortable when we started to add up the problems and wondering his quality of life, and you know, what fulfillment could he have out of this ...

In addition, the overall experience of families whose infants lived for more than two weeks (3 of the 12 participating families) seemed to be different from that of families whose infants lived only a short time. However, the small number of informants with this experience in this study prohibits drawing any conclusions about experience in relation to length of time spent in the NICU. One aspect of their stories stands out, however. Families whose infants lived for more than two weeks perceived a more active role for nurses in the

decision-making process. Nurses were more active in the following ways: suggesting a care conference to pull information together, being present for the actual discussion to consider W/W treatment and clarifying information presented, or preparing families for the upcoming discussion to consider limiting treatment options.

Context of Significant Themes

When parents described their experience of having to consider W/W treatment from their infants in the NICU, they did not explicitly describe a decision-making process. They described the context of the decision-making process. Nurses are not often mentioned by parents when they describe the discussions to consider W/W treatment from their infants. However, nurses are consistently identified as central figures in setting the context of the situation. Nurses may appear to be invisible in the decision-making process, but their influence is evident.

As parents told their stories, it became clear that some aspects of their overall NICU experience had an impact on their perceptions of the discussions to consider limiting treatment for their infant. Parents routinely mentioned nurses as key figures in these parts of the experience. Two aspects of the overall experience stand out: implementation of the decision and holding the infant.

First, as interviews progressed, it became clear to the researcher that how the decision was implemented influenced participants' memories of the discussions to consider W/W treatment. When asked about discussions to consider W/W treatment, nearly all of the

participants included rich descriptions of implementing the decision. Specifically, parents described in detail how they were helped through their infants' dying process.

Second, parents were profoundly moved when they were given an opportunity to hold their infants. Holding their infant had a dynamic effect on parents as they experienced the decision-making process. One mother knew her baby was going to die because following the discussion to consider limiting treatment, the nurses offered to let her hold him for the first time. One father said how helpful it was to be able to hold his son while he was warm and still had life, as he coped with the momentous decision about whether or not to continue life-support. While it meant different things to the various participants in this study, having parents hold their baby had the ultimate effect of moving the decision-making process forward.

It is difficult to summarize what many informants described as "the hardest thing I have ever had to do!." However, some significant themes emerged through data analysis that related directly to the purpose of this study, which is to improve understanding about and appreciation for what families experience during the crisis of ethical decision making in the NICU. Anecdotes in the form of text quotes are provided to illustrate the significant themes relevant to the study aims.

Significant Themes

In order to answer the central question of this research-- "How do parents describe their experience with and understanding of the

decision-making process used to consider W/W treatment from their infants in the NICU?"-- it is necessary to draw inferences from the significant themes found in parents' stories of their experience. Significant themes are presented in the context of the three aims of the study which focused on parents' involvement, the information they found helpful, and the meaning they found in providers' comments, advice, and behavior during the discussions to consider limiting life-support for their infants.

Involvement

The significant themes that emerged relevant to the aim of the study which focused on how parents felt about their level of involvement in the decision-making process included: participating, the nature of the relationship, responsiveness, control, and contact. These themes, woven together, reveal that not only did parents who participated in this study want to be involved, but in order for them to perceive their experience as positive, they had to feel involved in discussions to consider W/W treatment from their infants in the NICU. The majority of participants in this study felt involved in this process.

Participating. Feeling involved contributed to a positive experience for parents who had to consider W/W treatment from their infants. Feeling involved was central to their parenting experience. This experience was fundamental to their identity as parents. Feeling able to carry out their ethical obligations to their infants depended on

parents' perceptions about being involved in discussions to consider W/W treatment from their infants.

Nature of the relationship. The nature of the relationship was an identified theme relevant to involvement. Feeling involved depended to some extent on how parents described their relationship with providers. Effective involvement needed to be two-way. Believing that they were included in discussions to consider treatment options was essential in order for parents to feel involved.

Responsiveness. Parents expressed appreciation for providers who took time to become acquainted with them beyond conversations relevant to the critical nature of their infants' condition. This point came across in many different ways. Informants referred to providers' involvement with them in positive terms by giving examples of how providers took time to introduce themselves, talked about "normal" parenting concerns, spent time in an unhurried way to discuss the infant, or inquired about the parents' comfort needs, especially if the mother had been through a difficult delivery.

Control. Parents felt involved when they had a feeling that they were in control. They needed to feel they had choices and the power to exercise them. Without these, parents could not be parents. They had no way to carry out their ethical obligations toward their infant.

We said "Yeh, that is what we want." (withholding treatment) because we didn't ... I mean he had been through so much already, we didn't want to put him through any more, you know if we

absolutely could, just to you know, hold it back for a while (needlessly prolong death). They were really nice about it. You know, they told us, you know, that at anytime we could change our mind and let them know and they would go ahead and do it (the treatment) or whatever, but they gave us that option...

Even an informant who declined suggestions from providers to withdraw treatment felt in control. She felt free to disagree with providers' suggestions, and talked in a very positive way about her involvement and control over the decision.

I think they would have done whatever. You know, I definitely felt like from Dr. X that if we had wanted her to (be) resuscitated or, you know, that they would have done whatever we wanted...

Even though some parents did not want to make the final decision, they wanted to feel in control. One informant described it when she said

She [the doctor] said "you know, it is your decision. I can [make] you recommendations. We will do whatever you want to do , we can support him, take him off the ventilator"... I think we felt like we had complete control. So much [is] out of control that to at least feel like you can carry out your last wishes to the best of your ability for your child is very comforting... And I think we felt very much like now everything was [the baby], will make it evident what is best... So the decision was made for us by [the baby].

Feeling in control was central to feeling involved and having a positive experience of meeting their obligations as parents. More than one family felt that not only did they have control over the final decision, but also their wishes concerning when to implement the decision about W/W treatment were respected. It was not uncommon for parents to wish to delay implementation so that family members could gather to be with them and to meet the infant.

Contact. The negative experience of one family shows how much parents rely on provider-initiated contact to feel involved. Provider-initiated contact reflects how involved the provider feels in caring for the baby, but also how involved the provider believes parents should be in the decision-making process. One informant who did not feel involved described having to track down a physician to get information.

> They never.. they were supposed to call us and they never called us... they never called us to let us know what was going on,... it was almost as if, I mean we had to grab the doctors to find out what was going on, because no one told us nothing.

Meshed themes. In analyzing text, there were often examples where critical elements of text related to two different study aims, and illustrated tightly meshed themes. Some aspects of involvement were impossible to separate from themes relevant to information. For example, even when they stated they had no decision to make, parents felt involved if providers explained the situation and verified parents'

comprehension of the information. One informant stated that there was no decision to make. When asked if he felt involved he said,

It didn't sound like, you know, you get five minutes and then we are going to pull the cord if you don't. She was describing all the technical things that were wrong with him... She was just explaining real technically and (in) detail the complications. Basically, bringing me to the point (of) reasoning that there is nothing more that they could do. I didn't understand a lot of the language but I could see where she was going. I could see what she was trying to do and she was doing everything she could to reason with me to help me understand the conclusion that she was coming to, that they had come to.

Information

The significant themes that emerged relevant to the aim of the study which focused on parents' information needs included: need, comprehension, presentation, consistency, content (explained and observed suffering, quality of life, and biological functioning), beliefs/values, self-awareness, and trust. All these themes taken together reveal that the content of information, how it is presented, and when it is presented are linked to how parents feel about their level of involvement in the decision-making process.

Need. First and foremost, parents could not get too much information. Some information related to making choices. Some information related to wanting to understand a tragedy in their lives.

Parents were looking for any information which would help them interpret their infants' condition. While it may be possible to satisfy the need for information in order to make choices, it is also possible that the need for information in order to answer questions relating to the meaning of the tragedy may never be satisfied.

Comprehension. More than just information, they wanted to understand and comprehend the meaning. "I was digging at the questions, at trying to understand." Parents also mentioned how helpful it was to see x-rays or CAT scans of "normal" babies next to their infant's test results.

... Give us that knowledge you know, educate us so we can have some answers. We had to ask for his CAT scan. They said, "well, they told us what we needed to know." Well, show us, you know, I mean, you guys are getting all the answers, give us some of the answers too... Obviously we are not medical students and a lot of the stuff may be you know a little tough to understand, but it can be broken down. We will comprehend it if you just lay it out there.

Presentation. Parents wanted and appreciated information that was readily available to them. Parents who had a positive experience felt free to ask questions and believed they could get answers.

I was really afraid because I wanted to know, and I wanted to be able to ask questions, because this was complicated, you know, this was hard. They said "any time you have a question, you ask the nurse and they will call somebody to answer your question. If they can't

answer, they will get someone who can." and it was like that, and several times, you know we had them call the [specialist] so we could ask them questions and stuff, and it was really good because I was afraid that they would think that it was a bother and I didn't want to, but they were really helpful, you know. They said, "no, no problem, just give me a second and I will call them and page them and have them come here and talk to you." and I really appreciated that a lot.

Not only did they crave information, they appreciated it when providers were direct.

Everybody was really, you know, up front with us. They never hid anything and they never you know, polished things over for us, they always said what it was. They didn't want to tell us any different because they didn't want us to get false hopes and be crushed at the end..... I really appreciated it that they were so forward with us in not giving us false hope, but at the same time, it was really hard to deal with... Now that I look back, I am really glad that they did, because if they had given me any kind of false hopes at all, to hold on to I think that I would have been just ... lost it, I mean it would hurt when my son died, but because I knew before hand, that there was always that chance because everyone was honest about it, it wasn't so hard to take. I understand. I had longer to get ready for it..

When parents received direct information that was "up front" and not "sugar coated" they perceived it as truthful.

> The way that they said things to the fact of they were very straight forward and that they said that, they told the truth, you know, the truth was my son was very ill and they weren't sure that they could help him.

Many parents identified the difficulty in receiving direct information but nevertheless did not want "false hopes" and expressed appreciation for providers' honesty. It was not uncommon to hear comments similar to the following:

> I think the most important thing to us, or the most helpful thing to us is to be frequently updated, to be constantly informed, to be told honestly what is going on and the whole truth.... No matter how hard it is, it is much better for us to hear what is really going on and to not beat around the bush, or try to protect us.

"Up front" information was important to parents for another reason. It gave them more time to adjust. Parents who had prenatal diagnoses, as well as those who knew early after birth of the potential terminal nature of their infant's condition, all stated how grateful they were for the time to prepare.

Consistency. It is not unusual for infants in the NICU to be followed by multiple teams of physicians. Families with both positive and negative experiences identified this as a problem for many reasons. Without a consistent person to coordinate all the information, parents

were left trying to piece together information from multiple sources which made them feel left out of the process. One family's negative experience shows how vital it was for parents to receive well-coordinated information from a consistent source. These parents received a lot of information from a number of different sources yet still felt uninformed.

> ...We would walk in and they would be doing some tests on him that we had no idea was even ordered and that they were going to do and I realize you know, they need to do the tests when they need to do them, but you know, someone could have left a message with the nurse and said "You know, if the [parents] come in, tell them that we are doing a test on his [organ] and that these people will be here and, you know this is why we are doing it..." and I don't know, I don't know what their responsibility is to us, but you know, every time we turned around he was having, you know a test, poor little guy, you know, we were... didn't know why or you know, or anything... all we knew is he had a bad [organ]... We didn't know who was ordering all these tests, it didn't seem like anybody was gathering all the information... it was just like all this information was going into this black hole and somebody... it seemed like from long distance was ordering these tests and they, everybody would come and take a test, he would fail it and we are saying what the hell is going on, who is in charge of this whole person?

Parents wanted to know who was in charge. They wanted things to be laid out clearly from the very beginning. They wanted providers to identify their role in the care of their infants. This was particularly true for parents whose infants arrived in the evening, at night, or on weekends.

> I think they should take the time, take that five minutes, ten minutes or whatever, take the parent or whoever is over there visiting, take them aside and just lay all the ground rules and , say, "Okay, now this is the deal, your kid... your child is over here, I am Dr. or I am a registered nurse, whoever and this is my role and this.." you know, just lay it out so there is no questions, it is not like "well, you know, who is going to be watching him and who is going to be performing the tests and.." take that time, fifteen minutes and set aside.

Content, explained. Among other things, parents wanted to know what caused the problem, what the long-term consequences would be, what the short-term consequences would be, what could be done to treat the problem, and whether the infant would suffer. They were "dying for answers." More than one family mentioned looking up information in books to try to understand.

Content, observed. Parents determined this by report from the providers and through direct observation of their infants. When parents relayed to the investigator the information that convinced them everything had been done, or described their own observations of

their infants, they framed it in relation to the infants: "they [providers] said, his body was telling us," or "you could see how sick she was." One participant's comments powerfully articulate how she framed her decision in relation to her son.

> I just remember thinking and feeling like "Why, why am I doing this? I mean why am I putting him through so much when there is nothing left." I mean he hadn't cried, he hardly ever opened his eyes anymore, you could just tell that he was going and I just had a real feeling hopeless, like I couldn't do anything... and when they gave us that option [of stopping] it was like, "Okay, now I have a chance to do something (for her son)."

In this case, doing everything possible to help her son meant letting him go.

When parents were asked what information was important to them in trying to reach a decision about W/W treatment from their infants, they often responded with any one or a combination of three different types of information about their infants' condition. These types of information were consistent with Anspach's (1989) different ways of knowing, which come from technical, relational, and interactional cues.

Sometimes families related technical cues that illustrated an infant's biological functioning based on results of diagnostic tests (technical knowing). Other times they described perceptual cues that conveyed information obtained from direct observations of their

infants (relational knowing). Families also related information they obtained from interactions with providers or with their infants (interactional knowing). What seemed significant about parents' descriptions of important information was that often it included a value statement.

Beliefs, values. Parents often stated that it was easier to consider W/W treatment when they believed that health care providers had done everything reasonable they could to treat the infant. Believing everything had been done meant they had fulfilled their obligations to their infant. Knowing that providers had done everything in their power meant that the providers supported them as parents in their efforts to do what was best for their infant.

Parents gave concrete meaning to abstract information by assigning value to it and by relating it to existential consequences. Some examples include, "He had a 20% chance of being able to help him and that was pretty slim.", "They both had bleeding in their brains, which meant they wouldn't be normal, and we didn't want them to have to struggle through life.", or "You could see his body shutting down and we didn't want him to suffer." One final example demonstrates a combination of perceptual and interactional cues that contributed to formulating a value statement about the infant's condition,

We had seen him not feeling well, we had seen his vent settings going up higher, needing more support and being less active, less

responsive, swelling increasing. So we had all these physical signs and then how he interacted with us that were showing us that he wasn't doing very well.

In this case, the parents were able to process all the abstract information and physical information, assign a value to it, and give it meaning in terms of their son's existence.

While families did not universally mention one type of information in relating what was the most important information for them to consider as they contemplated their decision, comments about suffering and the infant's quality of life were very common. When talking about her twins, one informant said, "It was our decision to take them off, just because we didn't want them to struggle through life like that. We just wanted them to... you know, gosh, we didn't want to see them in pain any more." or "We very much looked at what his quality of life was, and how we would feel in that situation."

Self-awareness. Many parents showed a strong sense of self-awareness in weighing information when considering their options. One informant's comments illustrate this point nicely: " It would have made it easier for us [to continue], but not for the baby and he was our main concern."

Trust. Perhaps the most critical aspect of information parents were told by providers was not the information itself, but whether or not parents believed the information. Parents are constantly making observations about their infants. They interpret these observations and

give them meaning. When providers give parents information they must give meaning to the information. If parents' observed meaning about the baby's condition contradicted the informational meaning from providers, they were more inclined to believe what they saw. Parents struggle with the meanings they want and those they must accept. Whether or not this became an issue had much to do with their trust in the provider. To illustrate this point, two pieces of text are provided for contrast and comparison.

The first one is from a family who trusted the physicians and had a positive experience. The comments were made in a warm tone of voice, in the context of general positive comments about the experience. These nontextual, but contextual features of their comments indicated that they did not attribute anything but good intentions to the physician's comments. The parents understood and appreciated that the physician was trying to help them accept a meaning they didn't want.

> I don't know if they were consciously doing it, but I think they made him sound worse than he really was. We knew he was bad, and we knew he was terminal, but, they said you [the baby] can't hear... I know he was reacting to [the mother] when she was holding him... They would always just pass it off, "Oh that is just a motor reflex, he didn't hear you." You know, "Yeh, yeh he did." but maybe that is just being you know, parents...

The next example is from a family who doubted the physician and had a negative experience. The comments were made in harsh tones, with a raised voice in the context of general negative comments about their overall experience. The nontextual features of the comments indicated the participant's anger about the physician's comments. This informant felt that the physician dismissed her observations, and that her feelings and preferences in the decision-making process were not important to the physician. By doing this, the physician essentially prevented the participant from fulfilling her parental obligations to her infant. When asked whether or not she believed what she was told, she responded,

> No, because the things that they said he couldn't do, he could do,
> It was just real... She said he would never suck on a pacifier, well,
> he... he loved sucking on a pacifier. They said he would never eat
> and he ate. They said he could not recognize us, but yet when [the
> father]... especially [the father], [was there], he [the baby] would light
> up. I mean you could just see it in his eyes. So we knew that he
> was conscious...it was confusing. I mean they were telling you one
> thing, but yet another thing happened....

Meaning

The significant themes that emerged relevant to the aim of the study which focused on the meaning parents gave to providers' comments, advice, and behaviors during discussions to consider W/W treatment included: reality, vulnerability, compassion, parenting,

support, and caring. These themes reflect parents' struggle to discern the concrete meaning of information exchanged. These themes also show how parents were able to discover more abstract meanings to what was happening to their infants.

It is worth noting the absence of parents' comments directly related to perceptions of providers' clinical expertise. Nearly every family who participated in this study was referred to the institution where their infants received care and where they eventually had to consider limiting treatment. Families were referred either as a direct result of a critical birth event when the infant was transported or after some prenatal diagnosis that revealed that there was a problem with the fetus or that the mother's health was in jeopardy. For most of the participants, the implication of being referred to this institution was that their infant was receiving the best possible care.

To determine what meaning parents ascribed to providers' advice, comments, or behaviors, the investigator tried to understand and articulate parents' understandings of the implicit and explicit messages from providers which parents identified from discussions to consider W/W treatment. By encouraging parents to reveal their understanding of providers' messages, the investigator hoped to elicit comments that would reveal what meaning parents found in the communication. Parents were asked what providers did or said that was important to them during the discussion to consider treatment options, as a way of eliciting comments pertinent to the meaning of the

communication. Parents' comments about different aspects of their experience in the NICU often provided keys to unlocking the meaning they found in providers' communication during discussions to consider limiting treatment options for the infant.

Reality. Reality was a critical theme that emerged in the context of meaning. Parents could not move forward in their efforts to consider W/W treatment from their infants until the critical nature of the situation became real. The theme of reality relates to the abundant information parents received.

Parents had to process many sources of information. At some point, parents comprehend both the implicit and the explicit message found in all the information; namely that their infant would probably die. In addition to the technical information they received during discussions, parents identified other sources of information that made this point clear, including the presence of lots of people at their infant's bedside, providers' disregard for standard protocols, such as wearing protective clothing, in an attempt to help save the baby, or their breaking the rules to allow multiple family members to see the dying baby.

Many parents described the moment when the potential that their infant might die became a reality. This was especially true for parents whose infants lived for more than two weeks. Parents acknowledge being aware of their infants being seriously ill but not the awareness that "things were really that bad" until a provider made a

comment that conveyed to them the "reality" of their infant's situation.

> I didn't, I mean... you know how sick he is, but your mind won't let you know how really sick he is.. and when the doctor said that, [you could take him off the ventilator] it was like all of a sudden, it became reality, you know. Whoa, and I had to ask to reassure, "Is he really that sick? He's not going to come home?"

And in some cases, parents needed to be told the explicit message from crucial information. "She [the doctor] said we cannot intervene to fix it, and the nurse was saying, "Oh, I am so sorry," and we are like, wait, what does that mean?"

Vulnerability. Provider vulnerability was a powerful theme relevant to meaning. Parents expressed appreciation for providers who were able to convey the idea that they were not omnipotent. To parents, this made providers seem more humane. Vulnerability was implied in messages that related to either the uncertainty of the outcome or how providers used technology.

> I think, you know, that medical technology is so advanced now that the people that are involved in this heavy duty medical stuff and this was our thinking at that time... they'd maybe forget to think about... you know this is somebody's life we are dealing with that affects several other lives also. When we got down there we didn't find that they were that way...

For many parents, when providers explicitly acknowledged vulnerability, it meant that it was all right to consider and discuss limiting treatment for their infant. Parents seemed more open to the discussion about limiting treatment when providers acknowledged their vulnerability. More than one informant felt there was no real choice to make because providers related the message that there was nothing more they could do.

> I think if one can convey the reality that we are not God in the sense that we don't have control over these things, we don't have control over who lives or who dies... And if you [providers] can convey that truth somehow, some way and even not to a religious person... to somehow convey, the controlling factor, the bottom line factor in a way that they [parents] can see to remind them, and you know, we all know this, we know we have limitations and it is not like a mystery that only a doctor knows these things, but somehow convey it in that time of despair to bring it back to our memory so that we can make it make sense... maybe that has a lot to do with not being arrogant or self-realizing, you know she [the doctor] had limitations and she wasn't trying to be something more than she could be. She wasn't trying to convey to me, I am a doctor and you know, what I am saying, just the approach of not being arrogant and just... what it comes down to is this doctor... humble themselves, shown to the person that they convey things basically admitting to

the person that they have limitations and I think if they convey that to the person the person doesn't get so bent out of shape.

Compassion. This vulnerability also contributed to the perception that providers were compassionate.

I kind of always thought the doctors would just kind of deliver the information in a real objective manner and Dr. X was so compassionate, I mean, she would say, "This is really hard, you know, I want to give you all the information that I have so that you can make your decisions so that you understand what the situation was."

Parenting. When providers listened to parents and reassured them that they were making the right decision, to parents, this meant that their feelings and opinions were important. It reinforced the vital role they, as parents, played in being involved in making decisions. An example of this can be found in comments from an informant who was talking about the discussion to consider W/W treatment. "They made us feel like we were important, our feelings were important and they validated our feelings constantly."

Support. Providers sent the message that they could be counted on for support when they made themselves available to parents. This included being available to answer questions and encouraging parents to ask them, both after having time to digest information and prior to making the final decision.

They were really good to him and took real good care of him and explained a lot of what they were doing and we both had a lot of questions of what was going on and they were right there. They would answer every question we had...

Parents with positive experiences often remarked that providers made comments like, "If you have any questions, please don't hesitate to call. If I don't have the answer, I'll try to find someone who does." Parents who felt supported often made comments like, "They were there for us."

Caring. The theme of caring was central to the meaning parents found in their experience. Parents' perceptions about provider caring were pivotal to the significance of themes relevant to involvement and information. Parents perceived the implied message that providers were caring when providers said and did a wide variety of things. When providers initiated subtle physical contact, such as a hand on the shoulder, they were perceived by parents as caring. Providers who spent time with parents to converse about "normal baby stuff" conveyed the message that they cared about the baby and the parents as a family. Many parents made reference to providers "breaking the rules" for them and allowing extra family members to be at the bedside, or providers making arrangements for a private family room in their descriptions of providers' caring behaviors. One informant described it as "being there."

They had no problems with us being in there with him and they
didn't have a problem with that and you know they were always
there. They were just there all the time and that was the best part
They let us have that glimpse of hope, you know, and just kept
encouraging us, you know, "He is such a cutie and he is doing good
on his food today and oh look he had a bowel movement."
Caring reminds parents in a personal way how important they are to
their infant.

The showing of emotion, especially of grief on the providers'
part, was one powerful way parents identified providers' caring. When
physicians and nurses showed how they were emotionally affected by
the infant's condition, to parents this meant that the providers cared
about them as parents and the infant as a person. Believing providers
cared had a positive effect on the family. Perceptions that providers
cared had a powerful impact on how families experienced the crisis of
considering W/W treatment from their infants.

I think you got a sense that there were a lot of people who were...
you know, wanted desperately to try to make your child well and
that it grieved them that this baby was in this situation and I don't
think it is not necessarily important to see someone weep over my
child, per se, but it is helpful, and it is just immensely valuable to
have them express genuine emotions. I mean, I wasn't crying at
that time, and you know, she [the doctor] was, but I mean it
provides an atmosphere that it makes it easier to make these

difficult decisions when you feel like you are in an atmosphere of people who are supportive and caring and sensitive.

Perceptions that providers cared sent the message to parents that they were special. They were not just another family in a long line of families whose babies received treatment from the providers. Emotional connections were a powerful affirmation that providers acknowledged parents' ethical duties to their infants. It showed parents that providers respected the heavy burden on parents to fulfill their duty to their infants in the context of considering W/W treatment.

Meshed themes. As previously mentioned, sometimes critical elements of text related to more than one study aim. Significant themes relevant to meaning exist within the context of the overall experience (positive or negative). Often these themes were enmeshed with significant themes relevant to involvement and information. This tangle of themes revealed pivotal clues to comprehending the overall experience from parents' perspectives. For example, appreciating the complexity of the theme of *caring* under the aim relevant to meaning revealed greater depth to the theme of *responsiveness* under the aim for involvement and better understanding of the implications of the theme of *trust* under the aim of information.

Trust in the information a provider offered depended heavily on perceptions about how much the provider cared. When parents

believed providers cared, it meant they could be trusted. Again, a contrast between informants who had a positive and those who had a negative experience illustrates this point. First the positive experience.

Getting back to the decision-making process, I think...we were at their mercy, you know. I mean emotionally we were just wrecked and they were the experts and they are the doctors you know, and we were looking to them for answers, so whatever they said pretty much I mean we had no reason to doubt. ...they earned that trust, [the doctors] by showing that they were really caring, you know. If they at all seemed to be, to have an impression of you know, being mechanical and just going through the motions and there is so much emotional stuff tied to it, if they didn't show that they really cared about what they were doing, I suppose I would have questioned it a lot more. I think they really earned that respect and that trust.

Contrast the above text with comments from an informant who had a negative experience. From her story, it was clear that even though the information she received about her son's condition was accurate by her own accounts, this informant did not trust the information she was receiving. This informant did not believe providers cared. For her, this meant that whatever information providers supplied could not be trusted.

I think I would have wanted to hear the information a little bit differently. I wanted to know everything that they knew, and when

I first met with her [the doctor], I don't think she told me everything I really wanted to know.... I think it was more the way she delivered it [the information]. She was very cold.... I think if you are a doctor, or a nurse, I think you should let yourself connect. That is your job.

This informant felt the physician was "taking my hope away." The informant described her son's death as happening "exactly like she [the doctor] said it would," yet she felt that because the physician was "so cold" she was "giving up" on her son. The content of the message was blocked by the way in which it was delivered. More simply, how a provider delivers information matters at least as much as the information itself.

Summary

Qualitative data analysis for this research was not an ordered linear process by which understanding the themes pertinent to the aim specific to involvement came first, followed by the themes pertinent to the aim specific to information, and concluding with the themes pertinent to the aim specific to meaning. It was a circular investigation. Clarifying the significance of the identified themes for involvement and information depended on comprehending the complexity of the themes relevant to the aim specific to meaning. Articulating the significance of themes specific to the aim of meaning led to better understanding of themes specific to aims of involvement

and information, and consequently better comprehension of the themes for meaning.

Findings of this research provide clues about families' experiences with the process of deciding about W/W treatment from their infants in the NICU. These clues will help providers better understand what parents experience, and will help them to prepare parents to make decisions during the crisis of an ethical dilemma. In general, the findings support other investigators' earlier research and indicate that promoting effective communication exchange seems to have the greatest potential for enhancing the positive aspects of families' experience with ethical decision making in the NICU. When there was effective communication exchange between health care providers and parents, parents felt they, as the parents of a critically ill infant, were crucial decision makers for their infants. Findings have implications for practice as well as research.

Chapter 5: Discussion

This study was designed to improve understanding about and appreciation for what parents experience as they encounter the dilemma of having to consider W/W treatment from their infants in NICU. This research focused on parents' perceptions of their own experience with this emotional decision-making process. Significant themes identified through data analysis revealed that parents' experiences can be influenced by how involved they feel, the information they receive, and their perceptions about the implicit and explicit messages found in discussions with providers about limiting treatment options for their infants. This chapter discusses interpretations of the results in the context of the three study aims. It also discusses implications of the results for practice and research.

Interpretations of Results

The ultimate goal in interpreting the data of any qualitative research project is articulating the essence of the data as it relates to the stated aims of the research project. Interpretation of findings for this project involved an intense process of writing analysis interpretations, obtaining feedback from qualitative research experts and clinical experts in neonatal practice, and rewriting the interpretations. Interpretation is the final phase of analysis for qualitative research.

In order to generate understanding about parents' perceptions of their experiences with considering W/W treatment from their infants in the NICU, the researcher must reveal to the reader the significant

meanings parents found in that experience. The aims of this research focused on three key aspects of parents' recollections of this difficult experience: their feelings of involvement, the information they found helpful, and the meaning they found in providers' comments, advice, and behaviors. Examining the emergent themes relevant to each of these aims in the context of trying to generate understanding and an appreciation for parents' experience guided the researcher's interpretation and synthesis of the results from data analysis.

Involvement

The results from this study are consistent with information learned from parents in the Pinch (1990) and Pinch and Spielman (1996, 1990, 1989) studies. Parents in these studies did not feel involved in decisions but believed parents should be more involved. In the current study, parents' feelings about involvement were consistent with those of parents in the Able-Boone, Dokecki, and Smith (1989) and Schlomann and Fister (1995) studies. For informants in the current study, active involvement in decision making contributed to parents' feeling that they had control over their infants' treatment, that their wishes were respected, and thus that they were able to fulfill their ethical obligations to their infants. Information was a crucial element of involvement.

Information

Clear, accurate, well-coordinated, and timely exchange of information contributed to parents' positive retrospective perceptions

of their experience. This is consistent with research of families making ethical decisions about withdrawing treatment from adult relatives in acute treatment settings (Able-Boone, Dokecki, and Smith 1989; Tilden, Tolle, Garland, & Nelson, 1995), and research and literature describing how parents receive bad news about their children (Krahn, Hallum & Kime, 1993; Myers, 1983; Wooley, Stein, Forrest & Baum, 1989).

A return to the literature after completing data analysis revealed that parent preferences identified in the current study are consistent with a model proposed by Brody (1989) as a way of improving informed consent. Brody (1989) proposed a transparency standard that requires physicians to "engage in the typical patient-management thought process, only to do it out loud in language understandable to the patient" (p. 8). These parent preferences also support King's (1992) observations and speculations that using Brody's transparency model would reduce the risks of misunderstanding and improve parents' participation in the decision-making process in the NICU.

Parents in the current study wanted more than disclosure of information. They sought to understand the information. Parents wanted to know how physicians arrived at the point where they felt it was appropriate to consider W/W treatment from an infant. Parents needed physicians to make transparent their reasoning. For parents in this study, part of making this reasoning transparent included articulating values about the potential outcomes of each available

treatment option. Desiring information in language they could understand was true also for parents in the study by Schlomann and Fister (1995).

When providers are successful at making their reasoning transparent, treatment choices become clear. In the current study, when providers made clear to parents their reasoning about why they were considering W/W treatment from infants, parents were able to understand providers' perspectives. Parents did not describe having to make a difficult decision, because the choice about treatment had become clear.

Meaning

Parents needed help in interpreting the seriousness of their infants' illness. This was true also for participants in Pinch and Spielman's study (1990). Often informants in the current study were able to identify the moment when the meaning behind all the information became clear. In that moment, they realized that their infants would probably die. This moment happened when providers made comments that in effect translated the abstract meaning of the volumes of information presented in discussions into something concrete and comprehensible.

The meaning parents are seeking in the discussions to consider W/W treatment from their infants is that providers are considering this option because they have done "everything." Parents want to believe providers are offering this option because they are sincere and

compassionate. Outward expressions of grief by providers and demonstrations of support were just a few ways in which parents were given the feeling that providers cared. Provider caring is a common theme in other studies (Schlomann & Fister, 1995; Tilden, Tolle, Garland & Nelson, 1995). The caring, in and of itself, was not as significant to parents as the meaning they derived from the caring.

Providers' caring opened the door to trust, which facilitated information exchange about the infant's condition and limiting treatment options. Good information exchange made parents feel involved in the decision-making process. Being involved in this process validated the important role they, as parents, played in the life of their infants. Trust inspired by a caring context promoted parents' confidence in the information and the final decision.

Integration of Significant Themes

The crucial message found in all the themes significant to the study aims was that parents want to be parents. These people do not readily feel they are parents. We call them parents, but they have none of the usual parenting experiences. They cannot hold or feed their baby, or even change the baby's diapers. They need and want to be reassured they are parents.

The one thing the doctor really said was that I really appreciated was he says, "This is your child, it is my patient, but it is your child and you are the only one who can choose what is right for your child" and I really appreciated that.

This desire to be parents is consistent with Kirschbaum's (1996) findings that parents' sense of self was central to their experience of participating in ethical decision making for their children.

What makes this finding so significant is the degree of similarity between the current study and Kirschbaum's (1996) work. Kirschbaum's research used similar methods (phenomenological) with informants who had similar experiences (families who consented to limiting treatment options for their critically ill infants in the neonatal or pediatric intensive care unit) to reveal a central theme, that parents' sense of their role as parents was essential to the meaning they found in the experience. Kirschbaum's work, and the findings from the current study, support the notion that assessing parents' perceptions about their role as the responsible caregivers for their infants is a necessary step in creating a plan of care for the infant and his or her family.

One crucial way parents feel they are parents is to be involved in decisions about their baby's care. Gathering information and having control over decisions regarding their infant's care helps parents feel involved. They want to believe they are parents. Perceptions that providers care and are supportive reminds them in a personal way how important they are to their infant. It opens a connection and allows parents to trust information they are hearing, not just because the providers are experts, but because the providers are moved in a personal way by the circumstances of their infant.

If I look at not my loss, but look at the way that he was taken care of while he was there, and the people who took care of me and my husband pretty much, you know emotionally, they were always there and stuff like that. I would say that it was really, I mean a good experience in that sense that they really took the time every nurse did, you know they always introduced themselves to me and they told me, you know.. we would be sitting in there at night, you know holding the baby and the nurse would just talk to us like we were just normal people, you know and I really appreciated that.

Implications for Practice

The finding of the current study that parents want to be parents has deep implications for how nurses care for imperiled infants and their families. Caring for an infant in the NICU means caring for that infant who is part of a family unit. Parents' ability to make life support decisions for their infants depends on their ability to realize they are parents. Practically speaking, this means nurses must have an understanding of and appreciation for nursing care of the family, not just the hospitalized patient receiving their direct nursing care.

Nurses who provide care for imperiled infants must also provide care for the parents of these infants. Parents of critically ill infants need support and reminders that they are parents. Nurses play a major role in helping parents as they transition to becoming parents and as they realize their new family. Nurses must assess parents'

perceptions of themselves as parents of a critically ill infant, and work to foster their sense of self as the infant's parents.

Findings from the current study suggest that for nurses to improve their understanding for what parents experience during the crisis of considering W/W treatment from their infants, nurses must appreciate the significance of simple interventions. For example, having parents hold their infants, something nurses are generally responsible for facilitating, had the effect for every informant in the current study, of moving the decision-making process forward.

Supporting parents through the implementation process of W/W treatment from their infants had an equally profound impact on how families recollected the discussions to consider W/W treatment from their infants. Nurses provided unconditional support to parents during the dying process by helping them realize their role as parents of their imperiled infants. Simple interventions such as assisting parents to bathe their infants, collecting memorabilia, and simply being present during the dying process had an intense effect on parents during this difficult time.

Parents want to be involved in discussions concerning W/W treatment from their infants in the NICU. What role individual providers play in promoting this discussion is unclear. A common goal for providers is to help parents carry out their ethical obligations to their infants in the context of having to decide whether or not to

limit treatment for their infants. All members of the health care team must work to involve parents in ethical decision making in the NICU.

The ultimate goal to achieve in discussions to consider limiting treatment options for infants is clear communication, in which participants - parents and health care providers - try to avoid misunderstanding by making explicit the implicit messages they perceive. It is not enough to say the words, to give the information. Health care providers must verify the meaning parents find in the words. The challenge to providers is to reveal to parents the logic in their reasoning and to convey the compassionate motivation behind the options being considered. This is one way to make the decision-making process transparent to parents.

Past research has shown that effective communication between physicians and nurses is essential to keeping decision makers informed of the infant's status and parents' understanding of the situation (Able-Boone, Dokecki and Smith, 1989). Many authors believe (Novak, 1988: Rushton, 1990: Steele, 1987) and some research supports (Able-Boone, Dokecki and Smith, 1989) the idea that a crucial role for nurses is as facilitators of communication. In the current study, parent participants whose infants lived longer than two weeks readily identified this valuable role for nurses. These findings provide evidence that nurses acting in the communication facilitator role have a positive impact on families' experience with the decision-making process to consider W/W treatment from their infants.

Parents want to believe that providers are considering limiting treatment options for their infants because they are sincere and compassionate. Reaching a decision regarding W/W treatment from an infant is clearly an emotional and a moral choice. Parents believe that providers are sincere and compassionate when they initiate contact, when they provide clear, accurate, and timely information, and when they can express how they have been personally affected by the infant's condition. Nurses must develop ways to assess and communicate parents' perceptions of providers' caring, the content of the information they receive, and the process of how the information was shared. In addition, providers should be encouraged to seek constructive ways to express their caring and compassion to families.

Parents did not explicitly describe a decision-making process when they described their experience of having to consider W/W treatment from their infants in the NICU. However, parents clearly described the context of the decision-making process. Nurses are not responsible for providing information to parents in discussions to consider W/W treatment. However, by framing the context of discussions, nurses are in essence setting the stage for the receiving and processing of information by parents. Nurses' actions assist parents in feeling involved in the process by reminding them that they are parents.

The findings from the current study provide information for nurses about what parents experience in the crisis of considering W/W

treatment from their infants. Specifically, parents are helped in the decision-making process if they are helped to feel they are parents. Nurses' unique knowledge about parents of imperiled infants relates to their ability to assess parents as they transition to becoming parents. Nurses' contribution to the decision-making process relates to their ability to assist parents in feeling they are parents. Nurses can improve parents' experience at this difficult time if they focus on things that help parents feel they are parents - holding the baby, assisting in routine care for their infants, and talking about the baby as a whole person.

Parents in this study did not identify a visible role for nurses in discussions to consider W/W treatment from their infants. However, this does not mean nurses were insignificant in the decision-making process. Parents described in detail things that nurses did that made them feel they were parents. Feeling that they are parents is crucial to their sense that they are meeting their ethical obligations for their infants in the context of these difficult discussions. Nurses need to appreciate their role in helping parents feel that they are parents.

Nurses play a key role in setting a caring context for families as they experience the crisis of an ethical dilemma in the NICU. Setting a caring context lays the foundation for trust, which opens the door to communication. This suggests a powerful role for nurses with the potential for substantial influence on parents as they incorporate their imperiled infants into their families.

Implications for Research

Health care providers may turn to the literature in search of a framework or model that will help them resolve ethical dilemmas. Many potential decision-making models exist that might help in arriving at decisions that achieve this end, but no single model would fit every circumstance. The only link between the many models is the necessity for clear communication between decision makers. Nurses, if they intervene to facilitate information exchange, can promote a positive experience for parents who are involved in resolving the ethical dilemma of whether or not to limit treatment for their infants.

Any decision-making model that is used must be only a means of framing the information that is necessary in discussions to consider W/W treatment from infants in the NICU. Findings from this research suggest that a usable model would depend on establishing a caring context and trust to ensure the potential for clear communication exchange. Such a model would push participants to attempt to articulate their understanding of the facts, data, and evidence, and to clarify the value they place on each. This activity promotes conversation and dialogue about implied meanings and values, which by clarifying implied messages found in communication prevents misunderstandings that can lead to conflict. Further research is needed to design and test such a model.

Parents in the current study did not describe a clear decision-making process. However, they were able to articulate aspects of their

experience that had an influence on how they arrived at their decision to W/W treatment from their infants. There is a need for research to examine the influence nurses have on parents as they consider W/W treatment from their critically ill infants in the NICU. Such research should examine nurses' roles in assessing parents' as parents and in identifying what specific nursing interventions have a positive effect on parents' developing sense of self as parents of a critically ill infant.

By exploring, documenting, and articulating families' experiences with the crisis of having to consider W/W treatment from their infants, this research has laid the foundation for future research, particularly in exploring the role of the nurse in decision making. This research has shown that nurses have a clear role to play in setting the context for discussions to consider limiting treatment for infants in the NICU and in implementing decisions about W/W treatment from such infants. However, this research project was not designed to consider the less well defined role of the nurse in either arriving at the decision to approach parents about limiting treatment options for their infants or in actually discussing this possibility with parents.

Neonatal nurses strive to promote families' abilities to become families. One can assume that if parents are helped in their efforts to satisfy their ethical obligations to their infants they will be more likely to have a positive experience with the crisis of ethical decision making. This will contribute to their development as a family. Since promoting effective communication exchange has strong potential for enhancing

the positive aspects of families' experience with considering W/W treatment options, the challenge for nurse researchers and policy makers is defining and clarifying the nurses' role in promoting trust and enhancing effective communication between providers and parents in the NICU.

Parents' perceptions of the experience to consider W/W treatment from their infants in the NICU are linked with their impressions of providers' sincerity and compassion. There is no one identified feature about providers that would indicate the degree of their sincerity or compassion toward parents. Further studies are needed to explore how parents determine that providers are sincere and compassionate. This information could provide clues about how providers can establish parents' trust, which is crucial to parents' ability to hear and process information about their infants.

There are both similarities and striking differences in the methods, participants, and results of this study and those of recent published reports. How involved parents wish to be in making decisions appears to vary. It is not clear if variance is due to the demographics of the participants, the outcomes of the infants' treatment, or the providers' approaches to shared decision making. Parents' need for information is consistent across studies. Parents have to understand the information and its implications. Further studies should address how the parents' need for information is fulfilled,

including what evidence providers use to indicate they have satisfied this need.

However much the findings of this research have contributed to understanding parents' perceptions about the process of ethical decision making in the NICU, there remain questions that could guide further research. In discussions to consider treatment options, how do parents' and providers' perceptions of the decision-making process compare? What intervention strategies would improve information exchange between decision makers? If parents' trust in providers and the information they present can be enhanced by improving perceptions that providers care, what potential intervention strategies would achieve this goal? Some potential strategies warranting further study include: using role play to help providers find comfortable and appropriate ways to express their compassion for families while maintaining their professionalism, giving providers feedback on how clearly they present information, and providing structured opportunities for parents to discuss their understanding of all the information they have received.

<center>Limitations of the Study</center>

Findings for the current study must be considered within the context of the methods used for data generation. Parents described their recent experiences of participating in discussions to consider W/W treatment from their infants in the NICU. Their stories represented recollections of lived experiences. Recollections may be

altered by an individual's progression through the grieving process. In addition, retrospective recollections of the decision-making process may not be an entirely accurate representation of the lived experience, given that once the outcome of a decision is known, decision makers tend to have selective memory about the process (Mullen & Roth, 1991). The assumption behind the methods used in this study is that parents' retrospective accounts of discussions to consider limiting treatment options for their infants is an accurate reflection of well-being during the crisis of ethical decision making.

There are limits to the generalizability of findings for this study. First, while some parents differed with recommendations regarding W/W treatment, there were no real conflicts about which option to pursue. While the infants whose parents participated in this study had a wide variety of problems that brought them to the NICU, the participants themselves were a fairly homogeneous group. The experience of participants for this study may have been unique to this group because, on average, they had more education, because they were predominantly white, because they were moderately to very religious, or because most had health insurance, or for all of these reasons, some combination of them, or none of them.

In addition, all the participants' infants were treated in the same NICU. It is not clear how their experiences were affected by the culture of the NICU where their infants received treatment. Nor is it clear how individual providers may have affected participants' experiences.

Future studies should actively recruit participants who reflect ethnic, educational, economic, and religious diversity. In addition, future studies should attempt to determine the impact individual providers have on this experience and identify variations attributable to the NICU where infants receive treatment and ultimately where discussion takes place to consider limiting their treatment.

Conclusion

In conclusion, using the content and context of communication as a basis, qualitative research methods revealed significant themes relevant to the three aims of the study. Specifically, communication and information exchange between parents and health care providers has an impact on the experience of families. When parents receive accurate, honest, and timely exchange of information, they feel involved. The results also reveal that parents' perceptions about providers' level of caring can affect the level of trust they have in the providers and consequently their confidence in the information that is presented.

Positive experiences are marked by good communication exchange between providers and families. Hallmarks of good communication include a caring context, provider-initiated contact, frequent interaction, and lots of clearly explained information. Good communication is about more than information. It is about sharing and articulating the meaning of information. It is also about signs of caring about the baby and respecting parents as parents. When there is

good communication, parents are more likely to feel that providers are compassionate and caring, and that they can be trusted. This finding is consistent with research and literature relevant to communication between health care providers and patients and their families.

Parents want to be involved. Their ethical obligations to their infants require that they be involved. When parents felt involved in the decision-making process, they felt they were fulfilling their duty to take care of their infants. Again, being involved requires good exchange of information. Good information exchange depends on trust and making the meaning of the information transparent. When providers demonstrated caring to parents, it meant they could be trusted.

Ethicists debate appropriate theories and models to use to resolve ethical dilemmas such as the ones faced by the informants in this study. Parents do not explicitly describe a decision-making process. Nor do they identify ethical theories or models that were helpful to them as they struggled with the agonizing decision about whether or not to W/W treatment from their infant. Parents talk about being parents.

Nurses must assess parents as parents. They can effectively set a caring context for communication exchange by helping parents to realize their new role as parents. Nurses cannot make assumptions about information that is communicated to families. They must facilitate information exchange. Nurses must learn to verify the

intended messages in information shared in discussions to consider W/W treatment from infants. More importantly, nurses must determine how the messages are perceived by parents. Nurses must continue to examine their role in decision making, clearly define it, and determine interventions that will have a positive impact on how families experience the crisis of an ethical dilemma where they must consider W/W treatment from their critically ill infants.

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Appendix A

INTERVIEW GUIDE

Opening Remarks

Before we begin, let me thank you for your willingness to participate in this research study. You have been through a very difficult experience and I appreciate how sensitive this topic must be for you. I want to reassure you that if for some reason you are not comfortable answering any of my questions, feel free to say so.

I want to begin by telling you what I know about you. I know that you had a baby who was in the Neonatal intensive care unit at [name] Hospital. I know that the baby was very sick, that there was some discussion about difficult treatment choices and the baby eventually died.

My first question is

Closing Remarks

I would also like to collect some biographical information about you so I can compare the different families who are participating in this study. Would you mind answering some questions about that?

Your comments have been very helpful. I know that this was not an easy thing for you to do. If you have any questions that I can answer please do not hesitate to call. Sometimes people who participate in interviews feel upset and emotional after the interview is over and the interviewer is gone. If you are interested, I can give you the names of some community agencies or support groups that you could call if you feel like you want to talk more about this with someone.

Appendix A (continued)

INTERVIEW QUESTIONS

1. Tell me about (name of infant). (rapport building, and context setting)
       prompts: why was (s/he) in the NICU, what happened when they were in the NICU ....?;

2. I know that (name of infant) was very sick when s/he was in the NICU. There was some discussion about (withdrawing and or withholding) treatment when (s/he) was in the NICU. Tell me about the discussion about treatment options for (name of infant) and how you were involved.
       prompts: who was there, what prompted the discussion, what did you do or say, how did you feel, was it what you expected...?;

3. What information was shared during the discussion about treatment options and how did it affect the decision?
       prompts: what options for treatment were discussed, who shared information (you, doctors, nurses), did you have doubts...?;

4. What did the doctors, nurses or other health care providers do or say that was important to you in the discussion?
       prompts: Do you remember their words, how things were said...?;

5. What haven't we talked about that you think is important for me to know about the discussion to decide about treatment options for (name of infant)? (closure)

Appendix B

Study aims and codes with definitions

Instructions for raters:

Using the definitions, codes, and abbreviations provided, please code transcripts. Feel free to code directly on the transcripts using code abbreviations. Using the counting sheet, count the number of times each code appears.

Aim #1: 1) How did parents feel about their involvement in the decision-making process?

Aim #2: 2) What information was important to parents in reaching a decision about W/W treatment from their infant?

Aim #3: 3) What meaning did parents give to comments, advice and behaviors of health care providers involved in the process?

Aim 1: Involvement

Abbr	Code	Definition
INR	Nature of the Relationship	Descriptions of, or references to their (parents) relationship with providers
P	Participating	Active participation in discussions about treatment options (or lack of)
IR	Responsiveness	Confidence in care provider's sincerity (or lack of)
CTL	Control	Parents feeling they had power over the decision, choosing from presented options
IC	Contact	Provider initiated contact, (presence or absence)

Appendix B (continued)

Aim 2: Information

Abbr	Code	Definition
SA	Self-Awareness	Understanding of own beliefs, limits
IICS	Consistency	Changes in information content or changes in baby's condition
IIN	Need	Seeking information,
IIP	Presentation	Information availability (up front, honest)
IICM	Comprehension	Understanding of the jargon used
IITS ITQL ITB	Content Suffering Quality of Life Biological Functioning	As told to them (interactive cues) Comments relating infant's discomfort Comments relating to infant's or family's ability to experience life Test results, statistical prognostications (technological cues)
IOS IOB	Content Suffering Biological Functioning	As they can observe (perceptual cues) Perceptions about infant's discomfort Physical descriptions of infant's condition (coloring, responsiveness, puffiness)
IIT	Trust	Confidence in veracity of information (or lack of it), (honest information)
IO	Options	What was done for the baby "everything"
ICO	Coordination	Pulling information together
IFB	Framing / Baby	Framing information using the baby as the focus (baby as subject not object)
IBV	Beliefs / Values	Personal information about values, quality of life

Appendix B (continued)

Aim #3: Meaning

Abbr	Code	Definition
MC	Caring	Comments or provider behaviors that reveal a perception that health care providers were or were not concerned for what happens, and how families are affected
MSu	Support	Articulated comments or described behaviors relating to perceived support from health care providers (or lack of it)
MV	Validation	Articulated feelings that their participation and feelings were or were not important to providers in the decision-making
MRe	Reality	Articulated comments or behaviors that bring parents to the understanding that the baby will probably die
MCo	Compassion	Comments reflecting perceptions about providers' compassion (or lack of it)
MA	Appreciation	Articulated comments demonstrating appreciation for clinical expertise or demeanor of providers
MP	Parenting	Comments that reflect parents feeling that they are parents (not just people making decisions for a sick baby)
MV	Vulnerability	Articulated comments noting parents' perception that providers were aware of their own limits

Appendix B (continued)

Code Counting Sheet

Count	Abbr	Code
		Aim 1: Involvement
	INR	Nature of Relationship
	P	Participating
	IR	Responsiveness
	CTL	Control
	IC	Contact
		Aim 2: Information
	SA	Self-Awareness
	IICS	Consistency
	IIN	Need
	IIP	Presentation
	IICM	Comprehension
	IITS ITQL ITB	Content (as told) Suffering Quality of life Biological functioning
	IOS IOB	Content (as observed) Suffering Biological functioning
	IIT	Trust
	IO	Options
	IFB	Framing / Baby
	IBV	Beliefs / Values
		Aim 3: Meaning
	MC	Caring
	MSu	Support
	MV	Validation
	MRe	Reality
	MCc	Compassion
	MF	Parenting
	MV	Vulnerability