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I am submitting herewith a dissertation written by Kristina Maria Plaas entitled “‘Waiting for the Other Shoe to Drop’: The Lived Experience of Hope for Mothers of Premature Infants in the Neonatal Intensive Care Unit.” I have examined the final electronic copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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**“WAITING FOR THE OTHER SHOE TO DROP”:
THE LIVED EXPERIENCE OF HOPE
FOR MOTHERS OF PREMATURE INFANTS
IN THE NEONATAL INTENSIVE CARE UNIT**

A Dissertation Presented for the
Doctor of Philosophy Degree
The University of Tennessee, Knoxville

Kristina Maria Plaas

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DEDICATION

To Emily,

the little fuzzy red-haired girl
who lived in an isolette
and stopped breathing
and turned blue.

That was the day I,
a student nurse,
stopped breathing too
and my heart fluttered
and I fell in love
and was never the same.

Little Emily,
God bless you,
and God bless
the hundreds of preemies
that came behind you.
I loved you all.

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ABSTRACT

The purpose of this study was to describe the lived experience of hope for mothers of premature infants in the Neonatal Intensive Care Unit (NICU). This study was grounded in the existential-phenomenologic philosophy of Merleau-Ponty. A purposive sample of six mothers of infants born between 23 ½ and 31 weeks gestation were interviewed by the researcher 10 months to 2 ½ years after birth. Mothers were asked to think back to when their infant was in the NICU and tell about a specific time when they were aware of hope. Interviews were transcribed verbatim and analyzed following a hermeneutic process developed by Thomas & Pollio (2002).

Data analysis revealed consistent themes across participants. The contextual ground was the *World of the NICU*—a world in which uncertainty, powerlessness, and the marking of time from admission until discharge were set against the backdrop of an unfamiliar environment perceived as negative by mothers. In this context hope emerged from within the mother-infant relationship. Three themes were figural in the mothers' experience of hope: 1) hope and the infant, 2) hope and others, and 3) hope and the mother. Mothers took their cues to have hope directly from their infant(s). Discouraging or encouraging events dictated the extent to which mothers felt hopeful. Others had a powerful influence, either supporting or threatening mothers' fragile hope. Sub-themes in hope and the mother were: 1) lack of knowledge/uncertainty, 2) lack of control/powerlessness, and 3) feeling like a mother.

Noteworthy findings included the delayed onset of an awareness of hope—often several weeks after birth. Mothers focused solely on their infants; others became figural as they affected hope within the mother/infant dyad. They appreciated nurses who went the extra mile to encourage hope. The negative attitude or biting words of a single nurse quickly destroyed hope. Mothers rarely mentioned fathers, which suggests their lesser role in supporting hope. Mothers used the internet to reach out to others as there was limited opportunity for parent-to-parent interaction. They felt constrained to interact with other families by the emphasis on privacy related to HIPAA rules.

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION	1
Purpose of the Study	5
Research Question	5
Philosophic Perspectives in Existential Phenomenology	5
Assumptions	7
Researcher Perspective	7
Delimitations	9
Limitations	10
Significance	12
CHAPTER 2: LITERATURE REVIEW	14
Mothers and the NICU	14
<i>Historical Context of the NICU</i>	14
<i>Hope in Mothers of Premature Infants</i>	16
Hope in the Nursing Literature	22
<i>Concept Development and Definitions of Hope</i>	22
<i>Nursing Research on Hope</i>	25
CHAPTER 3: METHODS	32
Design	32
<i>Existential Phenomenology</i>	32
Procedure	35
<i>Participant Selection</i>	35
<i>Protection of Human Subjects</i>	36
<i>Setting</i>	36
<i>Procedure</i>	37
<i>Data Collection</i>	37
<i>Data Analysis</i>	38
Bracketing Interview	38
CHAPTER 4: FINDINGS	40
Thematic Structure	40
The World of the NICU: “A New Place for Me to Be”	41
<i>Uncertainty</i>	44
<i>Time</i>	45
<i>Powerlessness</i>	46
Theme 1: Hope and the Baby	47
<i>Discouraging Events</i>	47
<i>Encouraging Events</i>	50

Theme 2: Hope and Others	52
<i>NICU Professionals</i>	52
<i>Friends and Family</i>	56
Theme 3: Hope and the Mother	58
<i>Lack of Knowledge/Uncertainty</i>	58
<i>Lack of Control/Powerlessness</i>	63
<i>Feeling Like a Mother</i>	65
Summary	69
CHAPTER 5: DISCUSSION	71
Analysis of Findings	71
The Meaning of Hope	73
<i>Infant Cues</i>	73
<i>Benchmarking</i>	74
Highlights in Study Findings	75
Assumptions	77
Significance of Findings	79
<i>Hope in Mothers of Premature Infants</i>	79
<i>Hope in Nursing Science</i>	82
Strengths	84
Limitations	85
Implications for Nursing	86
<i>Education</i>	86
<i>Practice</i>	87
<i>Policy</i>	90
<i>Research</i>	91
Conclusion	91
LIST OF REFERENCES	93
APPENDIX	110
Informed Consent Statement	111
Demographic Data Form	113
Confidentiality Pledge of Research Group Member	116
VITA	117

CHAPTER ONE

INTRODUCTION

Prematurity is increasing in the United States. While the national birth rate and teen pregnancy rates have decreased to an all time low, the rate of preterm births has risen consistently over the past decade. The preterm birthrate, that is infants born prior to 37 completed weeks of gestation, has increased from 10.6 percent (per 1,000 live births) in 1990 to 12.1 percent in 2002. Almost 2 percent of infants are very premature, born at less than 32 weeks gestation. Prematurity is a leading cause of infant mortality and morbidity (Martin et al., 2003). Immediately after birth, most premature infants require specialized hospital care in a Neonatal Intensive Care Unit (NICU), an event that profoundly affects parents, family members, and friends.

Giving birth to a premature infant has been described as a time of crisis for the family (Best, 1993; Caplan, 1960; S. H. Johnson, 1979; Siegel, Gardner, & Merenstein, 1998). This crisis period is emotionally traumatic, especially for mothers who must cope with feelings of failure, guilt, and loss of the dreamed-for perfect infant (Brady-Fryer, 1994; Kaplan & Mason, 1960; Mercer, 1990; Stern, 1999). Physical, mechanical, and emotional separation of the mother and infant after birth interferes with the attachment process (Affonso, Hurst et al., 1992; Cox & Bialoskurski, 2001; Griffin, 1990; Klaus & Kennell, 1976). A sense of helplessness, loss of control, isolation, and a limited ability to provide care for the infant add to the emotional trauma experienced by these mothers as they struggle with fear, uncertainty, anxiety, and depression during the infant's NICU stay (Blackburn & Lowen, 1986; Casteel, 1990; Doering, Moser, & Dracup, 2000; Gennaro, Brooten, Roncoli, & Kumar, 1993; Gennaro, York, & Brooten, 1990; Lasby, Newton, Sherrow, Stainton, & McNeil, 1994; Maroney, 1994; McHaffie, 1990; Pinelli, 2000; Redshaw, 1997; Stern, 1999).

During the crisis of having a premature infant in the NICU, mothers have a tremendous need for support from friends and family members. Health care professionals also have a role to play in supporting mothers. Of all the NICU health care team members involved in the care of the infant and family, mothers spend the most time with nurses.

Therefore, neonatal nurses have primary responsibility for creating a nurturing environment which embraces the mother and supports her process of becoming the mother of a premature infant (Heerman, Wilson, & Wilhelm, 2005; McGrath, 2000; Miles, Carlson, & Brunssen, 1999).

According to Stern (1999), two basic principles serve as the foundation for the successful nursing care of mothers in the NICU. First, mothers must be provided with “a safe ‘holding environment’ from an experienced, accepting, and warm person” (p. S11), i.e. the nurse. There is a gentleness in this holding environment. The reassuring presence of a nurse allows the mother to feel validated. Thus supported, she is encouraged to explore her identity and role as a mother of a premature infant. The second principle reminds professionals that the mother “is like a fragile piece of china” (p. S11), vulnerable to positive and negative influences. Nurses must come to understand what having a premature infant requiring intensive care means for the mother. It is important for neonatal nurses to offer support which validates for the mother her new role as a mother of a premature infant in the NICU. Since new mothers are so fragile at this time, it is especially important that nurses avoid criticism or judgmental attitudes which could be destructive to this vulnerable mother.

Nurses desiring to work in the NICU undergo a period of intense orientation to prepare them to be competent neonatal nurses. Developmental milestones the new neonatal nurse is expected to attain include “improved organizational skills; ability to apply unit policies, procedures, and protocols; beginnings of family management activities; and the development of technical and interpersonal communication skills” (Maguire, 2000, p. 69). During orientation nurses are instructed to follow established practice standards and procedures, unit rules, and caregiving routines. While neonatal nurses are taught the basics of how to care for families in the NICU, the primary focus of orientation is the development of technical competency in providing care to infants in the high-tech world of the NICU (Harrigan & Perez, 1993). Given the complexity of the monitors and equipment in the NICU, it is logical that technical competency is emphasized in educating neonatal nurses. There is little room for error in caring for such

tiny, fragile patients. Meticulous attention to detail reduces the risk for error and increases the likelihood that subtle changes in the infant's condition will be detected quickly. Moreover, informal power and status are afforded to the most technically competent NICU nurses by their peers, a status not given to the neonatal nurse most competent in providing family-centered developmental care (Maguire, 2000; McGrath, 2000).

Neonatal nurses are expected to provide supportive care for the families, yet too many nurses fail to acknowledge and accept their role in caring for families, especially for mothers, as equal in importance to that of caring for the premature infant. With the strong emphasis placed on technical care of the infant, this disparity is easy to understand. Long-held attitudes and beliefs about the role of mothers in the NICU are reflected in established nursery rules and traditions. An aversion to change or hesitancy to extend beyond one's comfort zone often results in the reluctance of some neonatal nurses to relinquish long-established patterns of interaction with mothers of premature infants (McGrath, 2000; Miles & Frauman, 1993; D. B. Miller & Holditch-Davis, 1992). Supportive, holistic care of the mother is compromised by insufficient sensitivity to the individualized needs of mothers. It may be a lack of flexibility in planning or providing nursing care that jeopardizes holistic care of the mother. On the other hand it could be as simple as refusing to let go of past practices—practices which ultimately place the values and priorities of the nurse above those of the mother.

The body of nursing knowledge from research with mothers of premature infants continues to expand. We know much about the physical and psychological effects of preterm birth and the lasting impact of prematurity on families. Incorporating this knowledge into practice has been challenging, but family-friendly practices such as primary nursing, less restrictive visitation policies, early parental involvement in caregiving, parent support groups, kangaroo care, and developmentally supportive care are becoming commonplace in the NICU (Affonso, Bosque, Wahlberg, & Brady, 1993; D'Apolito, 1995; Lawhon, 1996, 2002; McGrath, 2000; Peters, 1998; Roman et al., 1995). Neonatal nurses are being taught the principles of family-centered care and are encouraged to implement them into practice (Ahmann, 1994; Ahmann & B. H. Johnson,

2000; Aita & Snider, 2003; Byers, Lowman et al., 2006; Dobbins, Bohlig, & Sutphen, 1994; Gretebeck, Shaffer, & Bishop-Kurylo, 1998; Harrison, 1993; McGrath, 2000; Shelton & Stepanek, 1994; Thurman, 1991). Established by the Association for the Care of Children's Health (ACCH), the principles of family-centered care affirm the family as the one constant in a child's life; the role of the health care professional, then, is to support the family in caring for the child. Parents are to be considered equal partners with professionals in providing health care, and family values, preferences, needs, and priorities should be identified and accommodated within a holistic plan of care for the child and family (National Center for Family-Centered Care, 1990; McAllister & Dionne, 2006).

Research conducted with mothers of premature infants has examined numerous aspects of having a critically-ill infant in the neonatal intensive care unit (NICU). Neonatal nursing practice has benefitted greatly from studies of the maternal role and attachment (Bialoskurski, Cox, & Hayes, 1999; Brady-Fryer, 1994; Cox & Bialoskurski, 2001; Mercer, 1984, 1990, 1995; Rubin, 1967a, 1967b, 1975, 1984), stress (Affonso, Hurst et al., 1992; Miles, Funk, & Carlson, 1993; Miles, Funk, & Kasper, 1992; Miles, Holditch-Davis, Burchinal, & Nelson, 1999; D. B. Miller & Holditch-Davis, 1992; Pinelli, 2000; Shields-Poe & Pinelli, 1997), caregiving (D'Apolito, 1995; Frank, Paredes, & Curtin, 1997; Griffin, 1990; Harrison, 1993; Lawhon, 1996; Miles & Frauman, 1993), and the psychosocial effects of having an infant in the NICU (Affleck & Tennen, 1991; Affleck, Tennen, & Rowe, 1991; Blackburn & Lowen, 1986; Casteel, 1990; Curran, Brighton, & Murphy, 1997; Gennaro, 1985, 1988; Meyer et al., 1995; Padden & Glenn, 1997; Stern, 1999). Nevertheless, many gaps remain in our knowledge of parents and families in the NICU. Much of the literature on parents comes from the nurse's perspective or has been collected using instruments which inevitably reflect the researcher's assumptions about what is important to parents, what parents experience, or what professionals want to know about parents. Only recently has qualitative methodology been used to facilitate the scientific documentation of parents' experiences (Hall, 2005; Higgins & Dullow, 2003; Holditch-Davis & Miles, 2000; Raines, 1996,

1998). While anecdotal reports about parents are plentiful, structured research, grounded in a holistic, caring philosophy, that gives parents an opportunity to tell their stories and share their innermost thoughts and feelings is sparse.

Purpose of the Study

The mother's experience of the NICU has not been adequately researched; in particular, the inner resources mothers draw upon for support during this crisis period have not been identified and fully explored. One of these inner resources, hope, was found to be important to mothers in a handful of reports in the literature over the past 40 years. While hope has been studied by nurses with numerous other patient populations, specific research on hope in mothers of premature infants has not been conducted. Still unknown are the nature of hope, what fosters hope, and how it is experienced by mothers of infants in the NICU. The purpose of this study, therefore, was to describe the lived experience of hope in mothers of premature infants in the NICU.

Research Question

This research sought to describe mothers' experiences of hope during NICU hospitalization of their premature infant. The research question which prompted this inquiry was: What is the lived experience of hope in mothers of premature infants in the NICU? The approach to existential-phenomenological research developed by Pollio and Thomas and their colleagues (Pollio, Henley, & Thompson, 1997; Thomas & Pollio, 2002) was selected for this study of mothers' hope.

Philosophic Perspectives in Existential Phenomenology

At a time when Cartesian dualism dominated philosophical thinking, Edmund Husserl introduced a philosophy of human consciousness known as phenomenology. According to Husserl, phenomenology is the study of things as they are directly experienced by the person, not as some scientist might interpret them to be. His desire was to examine things in their purest form as they are experienced in everyday life. Hence the motto "to the things themselves" reflected his attempt to describe pure phenomena,

the very essence of that given in the direct and immediate experience (Valle, King, & Halling, 1989).

Central to phenomenologic philosophy is Heidegger's notion of *Dasein*— i.e. all being is “being in the world” (Valle et al., 1989, p. 9). The world of which Heidegger speaks is not the world of natural science, rather it is the *Lebenswelt* or life-world—the world as lived by the person. Not a construction of consciousness, the life-world is coconstituted or cocreated in the dialogic relationship of person and world. It is in this unity of human-universe that the person exists and has meaning, for the person does not exist without the world and the world does not exist without the person.

A key concept in Husserlian phenomenology is *intentionality*. A basic structure of human experience, intentionality addresses the notion that all consciousness is a consciousness of something (Pollio, 1982). Situated within the dialogic relationship of person and world, every experience “has its reference or direction towards what is experienced” (Idhe, 1986, pp. 42-43). Intentionality emphasizes that human experience is “continuously directed toward a world that it never possesses in its entirety but toward which it is always directed” (Pollio et al., 1997, p. 7).

Also important in phenomenology are the Heideggerian concepts of *thrownness* and *freedom*. Perception is always an intercourse between the person and their world, that is the world has input on the person and the person projects their ideas upon the world. At times the person is “thrown” into the world in an undesirable manner and must find a way of dealing with the situation. When retreat from this new situation is not possible, the person must assume responsibility for their own being and becoming by projecting themselves forward with new possibilities—a concept known as *projected thrownness* (Thomas & Pollio, 2002).

The Danish philosopher, Kierkegaard, is considered to be the founder of existentialism. Addressing the concrete nature of man's existence was, for Kierkegaard, essential if philosophy was to understand the struggles of man in everyday life (Valle et al., 1989). Existentialism and phenomenology, when joined together, bring into unity a specific perspective of existence as it is humanly lived and a mode of inquiry which

allows this existence to be examined in a way which acknowledges the inherent presuppositions of the examiner (Pollio et al., 1997).

Phenomenology is an approach to experience established through a unique method of rigorous research, one in which the researcher must learn to “see phenomenologically” (Idhe, 1986, p. 15) as s/he engages in a dialogue with others. Through this reflective process one can come to a description of the experience as it is humanly lived (Pollio et al., 1997). When conducted from a Husserlian philosophy the focus of phenomenologic research is purely descriptive. The intent is to describe, not explain, the experience as lived, then to uncover the meaning of that experience. It is through this process of discovering the meaning in everyday experiences that phenomenology has applicability for nursing as researchers attempt to better understand the world of the patient and how nurses can better care for patients in that world.

Assumptions

The assumptions behind this study of hope were grounded in my years of experience caring for mothers and infants in the NICU. These assumptions were: 1) hope is inherent in mothers of premature infants, 2) neonatal nurses impact mothers' hope, 3) the NICU environment is detrimental to hope, and 4) personal religiosity affects hope. Secondary assumptions included: 1) mothers want direct, honest information from neonatal professionals and 2) mothers want greater freedom and flexibility to engage in mothering acts with their infants

Researcher Perspective

From the first time I cared for a premature infant as a student nurse, there stirred within me a passion for these, the tiniest of infants and their families. While it did not take long for me to master the techniques and technology of neonatal care, it was much more challenging to master my tender feelings for the babies and their families. Even when some of my colleagues openly admitted their dislike for visiting parents -- an annoying interruption to their schedule of tasks -- I enjoyed them. It didn't take long for

me to realize the uniqueness of each family, and with that realization came the forbidden desire to break established rules and practices in order to meet those individual family needs. As I gained experience, informal power, and seniority I frequently set aside the rules in order to more fully care for a mother, an infant, a family. While some of my colleagues were irritated by any nurse who did not fully comply with the rules, the families were acutely aware of the difference and were appreciative of my flexible approach to care.

Over the past two decades I have witnessed a remarkable change in the care of premature infants and their families. Most profound has been the scientific advances which have enabled professionals to successfully care for infants born as early as 22 weeks gestational age. Once I could do nothing more than watch helplessly as extremely premature infants lived for a few moments, then cry with their mothers because I was powerless to help their babies live. Now, after months of intensive care and *caring intensively*, most extremely premature infants survive and are taken home by their mothers. Over the years I have watched mothers in the NICU and listened to their voices—to the stories they tell. I have marveled at their strength, at their ability to live while facing the possibility of death, at their ability to stand unwavering, despite overwhelming adversity, and then move on. What is it that gives these mothers their strength? Where do they turn for support in this time of crisis? I believe there are answers to these questions -- answers that lie within the mothers' hearts and in their stories.

These stories— mothers' experiences of the NICU— have not been the focus of structured research. This gap in our understanding exists, in my opinion, not because mothers have been unwilling to share their thoughts and feelings, but because we, as nurse researchers, have not asked mothers to tell their stories. The constraints of a quantitative research do not permit research participants an opportunity to narrate their own experience or to share insights which can not be captured through a structured list of questions. Only a handful of qualitative studies with parents of premature infants have been conducted.

Based on my observations during 17 years of clinical experience, mothers of

premature infants experience hope, and hope is an important source of support and strength for them during the time their infants are hospitalized in the NICU. Yet only rarely have I seen hope openly acknowledged in the day-to-day environment of the NICU. To date, research has explored many other feelings such as fear, anxiety, and depression in mothers of prematures. Nurses have studied hope in many situations where patients and families face illness, stress, uncertainty, and sorrow. The close, caring relationships I have had with mothers of premature infants entrusted to my care has afforded me the privilege of seeing into the windows of mothers' souls, hearing their whispered pleas, and knowing of the many days where hope was the sustaining force which allowed them to carry on. While hope is mentioned in the perinatal nursing literature, nursing research exploring the experience of hope in childbearing women has not been conducted. In light of the unique nature of the childbearing experience for mothers of premature infants, research which specifically examines the experience of hope for mothers of premature infants is urgently needed to fill the gap in nursing knowledge. Such research can inform neonatal nurses what hope means for mothers in the NICU and encourage the implementation of nursing practices which improve the holistic care of premature infants and families.

Delimitations

Little is known about the experience of hope as it relates to preterm birth and admission of the premature infant to the NICU. As such, this study sought to elicit descriptions of hope as experienced within common situations found in the NICU. The delimitations of this study, intended to facilitate capture hope as experienced in these common situations, addressed four key areas: the study participant, the infant, the setting, and the condition or well-being of the infant and the participant.

The length of stay for premature infants in the NICU can range from a few days to four months or longer. Mothers who gave birth to a premature infant requiring NICU hospitalization for at least one week were the participants in this study. Every infant in the NICU has a mother that can be identified, whereas fathers or other persons significant

to the mother and infant may or may not be involved and available for study. The majority of existing research has been conducted with mothers, so more is known about the mother's experience of having a premature infant. Mothers are considered to be the most important and the most consistent person in the infant's life (Ahmann & B. H. Johnson, 2000; W. Brown, Pearl, & Carrasco, 1991) and are the persons most consistently involved with the infant during the period of NICU hospitalization; therefore, capturing mothers' experiences of hope most closely reflected the typical experience this study sought to understand. Because this study sought to describe the hope experiences of the most common type of NICU mother, mothers with unique situations which might affect their hope experience were excluded from this study.

The NICU provides specialized care for a vast array of critically-ill infants. While most of the infants are premature and have health conditions common to prematurity, full-term infants with conditions not usually found in premature infants are also cared for in the NICU. Once again, in order to reflect the most common NICU situation, only mothers of premature infants, irrespective of birth weight, were recruited for this study. Following the recommendation of an expert perinatal nurse researcher (D. Holditch-Davis, personal communication, February 2, 2001), it was decided that mothers could be approached about the study prior to NICU discharge although interviews would not commence until the infant had been at home for a minimum of one month. This decision was made because the mother needs time to adjust to having her infant at home and to develop confidence in her ability to independently care for her infant.

Limitations

There were several limitations associated with this study of mothers' hope. Choosing to study hope, a complex concept that defies easy definition or explanation, was an inherent limitation of this study. There is no consensus as to what hope is, what it means, what it does, or how it can be recognized; therefore, it was up to each mother to describe what hope was for her. This ambiguity set forth the potential for each mother to possess an understanding of hope that was distinctly different and bore no resemblance to

the hope described by another mother. If the descriptions provided by the mothers had been extremely diverse, it may have been difficult to develop an adequate thematic structure of hope in this initial study.

A study with mothers of hospitalized infants has limitations unique to this population. Since I was interested in the mother's experience of hope during the time her infant was in the NICU, it would seem logical to interview study participants while the infant was in the NICU. The experiences would be fresh in the mothers' minds and specific details may have been more easily recalled. Seasoned researchers, however, have discovered the opposite to be true. Their minds preoccupied with concerns about their infants, some mothers find it difficult to concentrate during this time. Thus distracted, they may have a hard time focusing on the researcher's questions or formulating a coherent response. Mothers need to feel confident their infant is getting the best possible care; thus, they will go to great lengths to cultivate optimal relationships with neonatal professionals. Because they have a tremendous need to be perceived of as good mothers of good babies, mothers are apt to give socially-desirable responses during hospitalization, even to researchers who are in no way connected with the care being provided. Unconvinced by reassurances of confidentiality and unwilling to risk retribution by angered NICU professionals, many mothers are reluctant to speak freely or say anything critical or negative about their experience while their infant resides in the NICU. To overcome this difficulty, interviews with mothers are best conducted after NICU discharge. Once at home, however, the mother may not be as able to fully describe her experience of hope. Limitations caused by delayed timing of the interviews may be offset, however, by reduced maternal fear and anxiety and a subsequent increase in her willingness to be open and frank with the researcher about her experiences of hope.

Since the interviews took place after hospital discharge, study participants were limited to mothers who lived in close proximity to the researcher or were able to meet at a location readily accessible to the researcher. A limited ability to travel to distant or rural communities could result in the exclusion of potential participants. Because the researcher was conversant in English only, mothers who were unable to hear, understand,

or speak English also were excluded from the study. Both geographic and language restrictions limited the potential diversity of study participants.

The use of phenomenologic methodology in this study also has its limits. With its emphasis on description of the human experience, phenomenology allows the researcher insight to the lived experience. It yields no causal explanations, however, nor does it offer support for or refute hypothetical questions as does quantitative research. While the usual interpretations of reliability, validity, and generalizability are not pertinent to qualitative research, standards of rigor do apply. Following a structured process for conducting phenomenologic research such as that described by Pollio and Thomas helps ensure rigor in the analysis of study data (Pollio et al., 1997; Thomas & Pollio, 2002). Successful implementation of this structured process should lead the researcher to uncover meanings in the participants' experiences that make sense to a reader with a similar background— in this study mothers of premature infants and neonatal professionals. Findings that are both plausible and illuminating become relevant when they are presented in such a way as to be of use to nurses in education, practice, and research (Sandelowski, 1997).

As this is the first study of the lived experience of hope for mothers of premature infants in the NICU, it is anticipated that the usefulness of this study will be limited to neonatal nurses providing care for mothers and infants of a similar nature to those participating in the study. Thematic coherence is possible after only a few interviews have been conducted (Pollio et al., 1997) with data saturation accomplished in as few as 6-12 interviews (Guest, Bunce, & Johnson, 2006). Given the constraints of the current study, the findings still should illuminate meaning and give nurses something to consider as they evaluate the manner in which they go about caring for mothers and infants.

Significance

Almost 12% of all infants born in the United States are born prematurely and prematurity is a leading cause of infant mortality and morbidity (Martin et al., 2003). Preterm birth and admission of the infant to the NICU is a time of crisis for the family, a time when mothers experience great uncertainty, anxiety and stress. Mothers need support

and encouragement from family, friends, and health care professionals during this time.

Holistic care in the NICU dictates that the nurse develop an understanding of each mother-infant dyad and what is important to that mother. What is the world like for this mother? What does having a premature infant mean to her? What strengths and resources are available to her in this time of crisis and what does she need from us as nurses to support her? Such an understanding cannot come from demographic information in a chart or from the pages of neonatal nursing books and journals; rather it comes only from being truly present with the mother, listening carefully to what she is and is not saying, and providing that gentle environment in which the mother will feel comfortable in trusting nurses with what is in her heart. Armed with this understanding, the nurse and mother together can establish a plan of care that is flexible, holistic, and meets the unique needs of this infant, mother, and family.

If mothers use hope to help them get through the difficult days and weeks of having a critically-ill premature infant in the NICU, and they have identified hope as significant to them during this time, and look to positive attitudes and communication from nurses and physicians for support and encouragement of their hope, then it is important for nurses and physicians to understand the mother's experience of hope so as to provide the support they need and expect. Since hope in mothers of premature infants has not been the focus of nursing research to date, there is a significant gap in our knowledge about mothers' hope. This study will contribute to nursing knowledge by illuminating mothers' experiences of hope during NICU hospitalization of their premature infants, eliciting an initial structure of hope in this unstudied population, and building upon existing nursing knowledge of hope. Finally, it is anticipated that the findings of this study will provide new insights for neonatal nurses about hope and mothers' experiences in the NICU, thus offering additional support for neonatal nurses as they provide holistic, family-centered care of mothers and infants in the NICU.

CHAPTER TWO

LITERATURE REVIEW

“To hope means to be ready at every moment for that which is not yet born, and yet not become desperate if there’s no birth in our lifetime” (Fromm, 1968, p. 9). Mothers of premature infants have a unique birth experience, one that extends beyond the immediate postpartum period to the time when the premature infant is discharged from the NICU weeks or months later. This study seeks to understand hope as experienced by mothers during the period of time their premature infants are in the NICU. The first section of this chapter is an abbreviated review of the literature on mothers in the NICU. Literature which links hope with mothers of premature infants is presented and the lack of nursing research on mothers’ hope revealed. Finally, a review of the state-of-the-science on hope research in nursing completes this chapter.

Mothers and the NICU

There is an abundance of literature about mothers of infants in the NICU. This literature began to surface in medical and psychiatric journals in the 1960s, shortly after the first NICUs were established in prominent university hospitals across America. Two historically-significant studies about mothers of premature infants are presented first, followed by a review of the nursing literature which associates hope with mothers of premature infants.

Historical Context of the NICU

Specialized care for premature infants began in France in the 1880s when the first human incubator was developed. Incubator use in the United States began in 1890 (Baker, 1991; Budin, 1907). The first special care unit for premature babies was opened in Chicago in the 1920s and the famous “child hatchery” of premature babies in incubators was exhibited at Coney Island. For the next 60 years, care of the premature infant focused on temperature control, feeding, avoiding infection, and treating disease. Until the early 1970s, parents were excluded from most NICUs as an infection control measure and had no contact with their infant until s/he was ready for discharge (Klaus & Kennel,

1976; O'Donnell, 1990; Sammons & Lewis, 1985).

Once parents were allowed entrance to the NICU, it was under highly restrictive conditions. Initially, brief visiting was permitted one or two times per week during a designated time period, although they were rarely allowed physical contact with their premature infant. Later, daily visits were permitted, but parents were required to scrub and don cover gowns and masks before being allowed to touch their infant through the incubator portholes (Klaus & Kennell, 1976; O'Donnell, 1990). Advancing science and technology in the care of sick and premature infants was of primary importance and care of the parents was a low priority. As specialized equipment and personnel in the NICU increased, parents were allowed little or no role in caring for their infant (Klaus & Kennell, 1976).

Early literature about parents of premature infants emerged in the 1960s with two seminal works. The first, authored by Kaplan and Mason (1960), described mothers' reactions to the birth of a premature infant as an acute emotional disorder. Their interpretation, grounded in crisis theory, proposed that this acute disorder was the result of the mother's attempt to cope with a threatening event for which she was unprepared. They identified four psychological tasks the mother must accomplish to successfully cope with the premature birth: (a) preparation for the possible loss of the infant, (b) acknowledgment of her failure to deliver a normal full-term infant, (c) resumption of the previously interrupted process of relating to her baby, and (d) development of an understanding of the special needs and growth patterns of her premature infant. It is important to note that this research was conducted at a time when parents were usually not allowed to have any contact with their infant prior to discharge, another plausible reason why mothers were so distressed

The second seminal work, conducted during the same time period at the Harvard School of Public Health, was by psychiatrist Gerald Caplan (1960). He analyzed case studies to identify patterns of parental responses to the crisis of premature birth. In particular, he was interested in identifying healthy and unhealthy responses to the crisis and level of mental health following the birth of a premature infant. Healthy outcomes

were found in parents who had a good cognitive understanding of the situation and were continually seeking information to form a reality-based assessment of the child. They had minimal distortion in their perceptions and were aware of problems. Likewise, they expressed feelings of anxiety or guilt and worked to maintain functional relationships. Unhealthy outcomes were associated with a lack of information seeking, little or no acknowledgment of the significance of the situation, distorted perceptions, suppressed negative feelings, blaming others, denial, and avoidance. Once again, forced separation from the infant could account for many of the unhealthy outcomes Caplan observed.

This historical overview of specialized hospital care for premature infants establishes the context in which premature infants were cared for by hospital personnel. Parents were almost completely excluded from establishing contact with or caring for their infant and they were given little information about their infant. Given this practice of isolation and exclusion, it's easy to envision the distressing responses expressed by these mothers. Yet ironically, Caplan (1960) was among the first to document a mother's expression of hopeful thoughts about her premature baby as a healthy way to handle her feelings about premature birth. Kaplan and Mason (1960) reported the common practice of physicians and nurses withholding information from parents: "We don't want you to feel the baby is better or worse so that you won't pin too much hope on what we say" (p. 542). Thus, early evidence exists linking hope with mothers of premature infants in spite of the deliberate actions of health care professionals to discourage hopefulness. Now, more than 40 years since these seminal studies were published, researchers have yet to investigate the hope experienced by mothers of premature infants.

Hope in Mothers of Premature Infants

Hope has been identified as important by parents of premature infants in anecdotal and research reports in the literature. This literature establishes the link between hope and mothers of premature infants, lends credence to the assumption that hope is significant, and reveals the dearth of research on hope in this population. The poignant stories and quotes from mothers are particularly telling of mothers' experiences of hope.

The first evening after giving birth to an extremely premature infant, one couple reported being very frightened and feeling as if they had nothing to build their hopes on (Christensen, 1977). One mother told of the valuable lesson she learned from a NICU nurse during the first day of her daughter's life — to balance hope with reality (Jed, 1999). Reflecting upon the sudden onset of pregnancy-induced hypertension and the unexpected birth of a premature infant, another mother said all her hopeful preparations for a healthy infant had ended in pain and anxiety: "We'd been expecting a bouquet and been handed a bomb" (Rapacki, 1991, p. 15).

Hope emerged as important to parents in research on chronic sorrow (Fraley, 1986). When parents were asked to identify their feelings surrounding the birth of their premature infant, hope was the third most frequent feeling reported. One parent declared "you never give up hope" (p. 116). In a Swedish study exploring the impact on families of having an a premature infant weighing less than 901 grams at birth (Stjernqvist, 1992), seventy-five percent of respondents (N=20) described the first few weeks as chaotic, a time when they did not dare to believe their infant would survive, and of having feelings of hope alternating with despair. Hope was found to be important in a study of the values of mothers of low birth weight (LBW) infants in the NICU (Raines, 1998); fathers of premature infants also reported having feelings of hope (Long & Smyth, 1998).

Researchers in a British hospital developed a questionnaire to evaluate the psycho-emotional care of parents of premature infants born prior to 32 completed weeks gestation (Curran et al., 1997). When asked to describe their feelings during their infant's stay in the hospital's NICU, hope was a common response. Thirty-three percent of parents (N=60) experienced hope initially after birth, 51% had hope during the NICU stay, and 46% reported feeling hopeful at the time of discharge. It is noteworthy that 83% of parents in the study expressed feelings to their partner, 63% to family members, and 35% to friends; only 36% of parents expressed their feelings to NICU nurses and 11% to physicians. This finding suggests that the NICU environment does not provide an emotional climate in which parents can feel comfortable in expressing their feelings, including feelings of hope.

In discussing study results, the researchers acknowledged feelings parents described—fear, anxiety, stress, and depression—that were consistent with the literature, although parents' reports of hope, confidence, and joy were ignored in this analysis. Rather, parents' reports of inadequate preparation for discharge and insufficient communication with physicians were emphasized. Researchers recommended establishing a system to improve parent access to physicians, adding a psychological counselor to the unit staff, and improving parental preparation for discharge home. There are several significant weaknesses in the study by Curran et al. (1997). First, questionnaire items were not disclosed and no mention was made of any attempt to establish reliability and validity of the questionnaire. It is unknown if parents were specifically asked if they had feelings of hope, depression, fear, etc., or if they volunteered this information without prompting. If they were directed to divulge these specific feelings, what questions were used to capture them? No information is given about sample selection, except to note that seventy-five percent of parents approached (N=60) agreed to participate in the study. No demographic information about parents or infants was reported. Because of the many flaws in this study, it contributes little to nursing knowledge about parents of premature infants. Reported findings served to duplicate what was already well-known and documented. In fact, the only unique findings from this study—parents' reports of feeling hope and joy—were completely ignored.

A Florida NICU was the setting for a study seeking to identify the differences in attitudes and perceptions by nurses and parents towards parental participation in caregiving (Frank et al., 1997). The study utilized a middle-range theory of parenting (Norris & Hoyer, 1993) derived from King's (1981) Theory of Goal Attainment, which addresses the changes parents undergo and the shifting role responsibilities between parents and nurses over the course of an infant's hospitalization. A convenience sample of 25 parents and 35 nurses from a large regional NICU completed a researcher-developed instrument derived from questionnaires by Gill (1993) and J. Brown and Ritchie (1990). No specific information is given about the content, reliability, or validity

of the instrument and no demographic data is presented to describe the study sample in this abbreviated research report. The setting and procedures for data collection and analysis are also absent.

Results indicated that parents placed a much higher priority on the nurses' responsibility to care for them than nurses perceived their responsibility to be—an affirmation of the premise that caring for parents remains a low priority for neonatal nurses. Interestingly, these same parents reported more satisfaction with nurse/parent relationships than did the nurses. Nurses and parents also differed in their perceptions of the nurse's ability to adequately care for parents in the NICU. While parents expressed confidence that nurses were prepared to meet their needs and were comfortable interacting with parents, nurses reported feeling much less prepared and less comfortable in interacting with parents. Once again, this study provides evidence of the insufficient emphasis placed on caring for parents in neonatal nursing education and practice. Study results showed that parents also varied in the priority they placed on being told about positive changes in the infant's condition. While parents were always notified of negative changes in their infant's condition, they desired more communication from the professional staff about positive changes. Parents valued the positive reports as supporting the hope they had for their infants. In the brevity of this research report, much of the information needed to assess the quality of this study is not available, thus limiting its usefulness. It is unclear how researchers established a relationship between parents' desires for positive changes to be reported and hope, thus leaving the reader with more questions about what data were collected and how they were analyzed and interpreted. Nevertheless, the study did indicate continued neglect in the care of parents in the NICU and supports the need for research on hope in parents of premature infants.

When asked about their recollections of having a premature infant in the NICU, African American mothers of premature infants frequently referred to their spirituality (Miles, Wilson, & Docherty, 1999). Finding hope was one of the four major themes elicited after transcript analysis of interviews with 15 mothers. They specifically spoke of finding hope despite the severity of their infant's illness. Almost all mothers reported

feeling hopeful for their infants and used varying strategies to support this hope. Gathering information was one of the most important strategies mothers used to maintain hope. Talking with physicians and nurses, friends and family members, and reading books about prematurity helped them to understand their infant's illness and care. Prayer and relying on God helped mothers to overcome feelings of helplessness. One mother prayed, "Dear God, please don't let nothing happen to her, or at least let me be there so I can say goodbye" (p. 21). Some assumed a fatalistic attitude about their infant and declared it was God's will if their baby should die. While several mothers reported feeling closer to God and having more faith, others became bitter and withdrew from God despite a strong religious tradition. Reading the Bible, attending church, and the prayers of family and friends were identified as adding to the hope mothers felt. Watching for cues from the infant also helped mothers find hope.

This study was unique in several ways. First, it is the only study I've uncovered which specifically explored the experiences of African American mothers of premature infants, an identified at-risk population with a high incidence of preterm births. Second, this study was sufficiently open to allow mothers to reveal those aspects most figural to their NICU experience. Consequently, these mothers spoke at length about the role of spirituality during their NICU experience, an important dimension of holistic care which has been largely neglected in the neonatal literature. The repeated reference to hope by the mothers in this study revealed the need for the present study of the lived experience of hope in mothers of premature infants.

One study of hope in mothers of premature infants was found in the literature (Sherman, Baska, & Hertzog, 1995). This study examined hope, perceived burden, and satisfaction in 20 mothers of premature infants weighing less than 1,000 grams at birth (experimental group) and 19 mothers of infants born at term (comparison group). Mothers were approached about participating in the study when their infants were 12 months corrected chronological age. The two groups of mothers--matched for age, parity, ethnicity and socioeconomic status--participated in semi-structured interviews intended to capture their experiences of caring for their infants after discharge from the NICU. They

were asked to describe the overall condition of their infant, what they did and did not enjoy doing with the infant, how easy or difficult the infant was to care for, what their worries were, and what they expected their infant to be like at three and five years of age. Satisfaction with the infant was measured using the Carey Temperament Scale (1=easy, 4=difficult); hope was measured by the Vineland Social Maturity Scale (1=no hope, 5=extremely hopeful), which assessed mothers' expectations that her infant would ultimately live a happy, healthy, self-sufficient life; perceived burden was measured using the Impact on the Family Scale (1=great impact, 4=no impact); and infant development was assessed using the Denver Developmental Test (1=normal, 4=untestable). No information was given about the reliability and validity of the instruments used. It is unclear how the study instruments were administered and what items or subscales were included, although reported results suggest that single items were taken from the Vineland Social Maturity Scale and Impact on the Family Scale to assess hope and burden respectively, thus decreasing the credibility of results.

There was no significant difference between the groups in perceived burden and impact on the family. The premature infants ($M = 1.95$) were viewed as slightly more difficult than term infants ($M = 1.58$, $p = 0.10$). Mothers of premature infants were slightly less satisfied ($M = 4.38$) and less hopeful ($M = 4.43$) than the mothers of term infants ($M = 4.71$, $p = 0.04$; $M = 4.82$, $p = 0.03$). Mothers were more likely to be less satisfied, less hopeful, and more burdened if the infants were perceived as having difficult temperaments or had developmental abnormalities.

While this study represents a first attempt to assess hope, the instrument used was a poor measure of hope. Rather than inquiring about hope, the question in this instrument asks mothers to predict the future and whether or not their infant will be happy or self-sufficient at 3 and 5 years of age—ages when children are usually not self-sufficient. This study is plagued by other theoretical and methodological errors. The poor, overly simplistic operationalization of variables and poor choice of study instruments, compounded by the lack of data supporting the reliability and validity of study instruments, the lack of clarity of relationships to be tested, and an inadequate sample size

limit the usefulness of the data. Additionally, this study focused on the mother's perceptions and experiences a year after the infant was in the NICU, not during the neonatal period.

With all that has been written about how mothers respond to premature birth, few authors mention hope as a part of the mother's experience. Possibly this oversight reflects the reluctance of neonatal nurses to acknowledge the importance of non-medical concepts such as hope, courage, or respect. Perhaps hope is not viewed as a problem to be reckoned with in the same way that depression, anxiety, or anger might be. Maybe it is simply because research on neonatal technocare is valued more than research on holistic care of the entire family unit. Is it assumed that somehow neonatal nurses know what mothers are experiencing and what care they need? Whatever the reason, a gap in nursing knowledge about hope in mothers of premature infants in the NICU exists. Research is needed to understand hope as experienced by these mothers entrusted to our nursing care.

Hope in the Nursing Literature

Scholars from many disciplines have studied hope during the 20th century, including philosophy (Bloch, 1959/1986; Marcel, 1962), theology (Lamb & Lamb, 1971; Lynch, 1965/1974; Moltmann, 1975), sociology (Fromm, 1968; Desroche, 1979), and psychology (Synder, 1994; Stotland, 1969). Nurses have drawn upon the writings of these scholars for concept development, research, and knowledge building on hope for the discipline of nursing. While I have reviewed an extensive body of hope literature, only key works that develop and define the concept of hope for nursing are included in this review. Likewise, selected qualitative nursing research on hope also was reviewed.

Concept Development and Definitions of Hope

There is a burgeoning body of nursing literature on hope. Nurse scholars have done extensive work using the procedures of concept analysis to explore the many facets of hope. From these analyses attributes of hope have been described, definitions proposed, and instruments developed to advance the study of hope in nursing.

In a classic treatise on hope, Vailliot (1970) reminded nurses that the objective of nursing is to help the patient live as full a life as possible, and asserted that inspiring hope is the specific task of nursing. Drawing upon the writings of Marcel (1962), an existential philosopher, Vailliot noted that hope is not optimism or desire; optimism is superficial and self-centered, whereas hope “springs from the depths of one’s being” (Vailliot, 1970, p. 271). With hope, the person believes he or she will be made whole again. This wholeness is not simply a return to one’s previous state of being, but is a transformation: “It is never a simple return to the status quo...it is that and much more, and even the contrary of that: an undreamed of promotion, a transfiguration?” (Marcel, 1962, p. 67). Vailliot cautioned, “any situation justifying hope is, by definition, not amenable to strictly ordinary means, and hope sets its goals beyond mere human provisions” (p. 271). Vailliot’s discourse on hope is among the earliest in nursing and is frequently cited in the literature; however, this work reflects the spiritual and religious beliefs and personal knowing of the author rather than on conclusions derived from research studies. It is noteworthy that Vailliot (1966) was among the first nurses to embrace existential philosophy, with its emphasis on the unique value and nature of the individual, thereby charging nurses with the responsibility of being wholly present to the suffering and experience of each person, and of providing sensitive care to meet the unique needs of the individual.

Nursing scholars have found hope to be a complex, multidimensional concept. . While there are similarities among the definitions of hope by nurses, there remains no clear consensus as to what constitutes hope. In a frequently cited analysis of hope, Dufault & Martocchio (1985) categorized hope into two spheres—generalized and particularized, and six dimensions— affective, affiliative, behavioral, cognitive, contextual, and temporal, thus acknowledging the potential presence of hope in any aspect of one’s life. They found hope to be “a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant” (p. 380).

The complexity of hope is captured in the clear, concise definition of hope by Farran, Herth, and Popovich (1995), another definition frequently cited in the literature:

Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating oneself and one's world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present (p. 6).

Similar elements are found in Stephenson's (1991) definition of hope as "a process of anticipation that involves the interaction of thinking, acting, feeling, and relating, and is directed toward a future fulfillment that is personally meaningful" (p. 1459). Parse (1990, 1999a) declared hope to be a universal lived experience of health, while Travelbee (1971) proclaimed hope as necessary for a person to be emotionally and spiritually healthy. There are six critical attributes of hope, according to Nowotny (1986): 1) future orientation, 2) active involvement, 3) comes from within, 4) is possible, 5) relates to others or a higher power, and 6) is meaningful to the person.

The writings of Fromm, Marcel, and Stotland provided the philosophical foundation for J. F. Miller's (1983) theory of hope in nursing. Hope was conceptualized as "a state of being characterized by an anticipation for continued good state, an improved state, or a release from perceived entrapment" (J. F. Miller & Powers, 1988, p. 6). Ten critical elements of hope were drawn from a comprehensive review of the literature in nursing, philosophy, theology, and psychology and from a qualitative study of 59 persons who survived a critical illness: mutuality-affiliation, a sense of the possible, avoidance of absolutizing, anticipation, achieving goals, psychological well-being and coping, purpose and meaning in life, freedom, reality surveillance-optimism, and mental and physical activation (pp. 6-7). These ten elements provided the framework for the development of a model of hope in chronic illness (J. F. Miller, 1983, 2000) and for the Miller Hope Scale (J. F. Miller & Powers, 1988). In Miller's model of hope, a connection between psychic energy, hope, and despair at three different levels is proposed—the first level of hope being superficial wishes which require little energy and no despair and a third level being a hope for relief from pain, suffering, or entrapment which totally encompass one's psychic energy and lead to a despair so deep that one is almost ready to give up.

In the second section of her hope theory, J. F. Miller (1983, 2000) associates hope and hopelessness with powerlessness, immobilization, low-self-esteem and depression, despair, and the possibility for self-harm in a cyclical model of hopelessness and powerlessness. The nurse's role to inspire hope is presented in the third model. Grounded in existential thought, the role of the nurse is to help the patient to be-in-the-world, fully experiencing the little things in life and constantly striving to improve one's own being. The nurse supports the patient in using reality surveillance (Wright & Shontz, 1968) to find clues in their world which substantiate their hope, in setting and revising goals so the patient has something to anticipate and work toward, in adopting a life-promoting framework (Wright, 1980), and in embracing spiritual practices which assist the patient in finding a sense of meaning and purpose in life. The nurse emphasizes to the patient the importance of sustaining relationships and connection with others, expanding coping skills, adjusting to temporary changes in control while avoiding feelings of powerlessness (J. F. Miller, 1983, 2000).

Nursing Research on Hope

The many analyses and definitions of hope by nurses provide the foundation for the development and expansion of nursing knowledge about this important concept. Research has been used not only to identify critical attributes of hope, but to establish instruments to quantify hope, derive theories about hope, and to test the theories and assumptions nurses have about hope. The substantive body of quantitative research on hope has been the subject of several scholarly reviews (Farran et al., 1995; Kylmä & Vehviläinen-Julkunen, 1997) and will not be included here. Rather, emphasis is placed on a review of qualitative research on hope in nursing, particularly phenomenologic research conducted with parents and family members of ill persons.

Recently there has been a developing trend to use qualitative research methodologies in the study of hope. Techniques of participant observation, semi-structured interviews, grounded theory, and phenomenology have all been used to capture the first-person meaning of hope for patients. Additionally, qualitative research has been used in developing the hope instruments used by nurses in quantitative research. A

qualitative study of critically ill patients was used in the development of the Miller Hope Scale (J. F. Miller & Powers, 1988). After conducting interviews with 25 adolescents, Hinds (1984) used grounded theory to establish a construct definition of hope. This definition and structure of hope served as the foundation for the development of the Hopefulness Scale for Adolescents (HSA) (Hinds & Gattuso, 1991), a scale subsequently used to study hope in adolescents with cancer (Hinds, Quargnenti, et al., 1999). The HSA was also used in a study of hopefulness, self-esteem, and perceived social support among pregnant and nonpregnant adolescents (Connelly, 1998).

Phenomenology, with its emphasis on describing meanings in a person's experience of everyday life, has become an increasingly popular approach to the study of hope. Benzein, Norberg, and Saveman (1998) conceptualized hope as existing within the spiritual dimension of the person in a phenomenologic study of healthy Pentacostalists in Sweden. Hope was inextricably linked with faith, both on earth and in heaven, and could only be understood by those who have a personal relationship with God. Participants' ultimate hope was to meet with Christ in heaven and live with Him eternally. Hope was strengthened through reading the Bible, saying prayers to God, and sharing their Christian beliefs and values with others. In a later study with healthy non-religious Swedes, hope was found to be related to being and doing (Benzein, Saveman, & Norberg 2000). Participants described hope as (1) an inner feeling that makes a person want to live; (2) participating in something bigger than themselves, "like a stitch in a net" (p. 307); (3) having energy, wanting to do things, and making plans and having expectations for the future; and (4) having the courage to set new goals once previous goals have been accomplished. From these two studies one can readily see a distinct contrast in the meaning of hope for persons with differing values and perspectives—an important consideration for this study of mothers' hope.

The proposed study of hope in mothers of premature infants examines hope as experienced by someone other than the ill person. Phenomenology has been used in several such studies exploring hope in family members of an ill person. Gelling (1999) interviewed the relatives of seven patients with severe head injuries admitted to the

neurosciences critical care unit (NCCU). The relatives of consecutively admitted head-injured patients were approached about the study after the patient had been in the NCCU for at least 48 hours, and all agreed to participate. The patients were between 28 and 50 years of age and had been in the NCCU between 64 - 145 hours at the time interviews with the family members were conducted. After audiotapes were transcribed, they were first returned to the participants to verify the accuracy of the content. Then NUD-IST 4 software was used in conjunction with Colaizzi's method of analysis to review transcripts, code the data, and elicit themes. Identified themes were then reviewed and verified with study participants.

Emergent themes in this study included relationships, information, loss of control, emotions, and the temporal dimensions of past, present, and future. Participants emphasized the importance of relationships with the nurses, physicians, family members, friends, the patient, and relatives of other patients in providing a foundation upon which to build their hope. Family members were particularly aware of the supportive caregiving and professional commitment of the nurses. Because of the potentially negative reality of the situation they often relayed to the family, physicians were sometimes viewed as less supportive of hope. Despite this perception, providing clear information to the family was also valued as family members attempted to formulate hope in the midst of uncertainty. Experiences of the past, present, and future helped family members to place things in context and make sense of them. Maintaining some measure of control, however small, was important for relatives to be able to focus on realistic hope. Hope also was important as relatives dealt with the emotional impact of their injured loved one, especially in terms of the fear of death or permanent brain-damage.

From the research report, it was clear that Gelling's (1999) study was carefully planned and took into consideration the sensitive nature of interviewing family members of patients in the NCCU. The detail presented about study procedures and data analysis encourages reader confidence in the report. Moreover, the trustworthiness criteria of credibility, transferability, dependability, and confirmability were also addressed and the generous use of quotes from participants supported identified themes and highlighted the

significance of hope for this population. In short, this research established the effectiveness of using phenomenologic methods to study parents' hope, documented the importance of hope for families of ill persons, and offered support for the proposed study of hope in mothers of premature infants in the NICU.

The lived experience of the family of a head injured patient was the topic of another phenomenologic study (B. P. Johnson, 1995). Rogers' (1970) *Science of Unitary Human Beings* provided the theoretical framework for the study and Van Manen's approach to phenomenologic research was employed. The parents and four teenage siblings were asked to relate their thoughts and memories from the night of their brother's accident. The parents and siblings transcripts were analyzed independently at first, then aggregated when the emergent themes were found to be similar in both groups. Among the themes elicited were helplessness and the need to hope, and being informed and involved. While the specific intent of this study was not to examine hope, it was figural in the family's experience. The results of this study supported previous research in adult critical care units which identified hope as important to family members of ill persons. If hope is significant to families in other areas of critical care, then it seems logical that hope is also significant in the NICU. The present study of mothers' hope took a first step towards answering this question.

Family members of patients with end-stage renal disease were interviewed about their experience of waiting for a cadaveric renal transplant (Sloan & Gittings, 1999). The patients had been selected as alternate recipients for a donor organ, a practice used to minimize the risk of wasting an organ if for some reason the primary recipient was not able to undergo implantation. Study participants, family members and patients who were admitted and prepared for surgery but did not receive the organ, were interviewed about their experience of leaving the hospital without the anticipated transplant. Themes culled from the transcripts included wanting the organ, but not at the expense of someone else, knowing and not knowing, having high hopes for a life without dialysis, and not having a voice for their experience. The patients' hopes were high after they were notified about the potentially available organ. This high was rapidly replaced with an experience of

profound disappointment and loss when they did not get the organ, despite the fact they were told they were second in line for the transplant. The patients' reality of the experience was vastly different from that of the health care team members, and patients felt they had no voice to express how they felt. The findings of this study highlight the potentially devastating effect health care team members and standard hospital practices can have on the hopes of patients and families. Asking mothers of premature infants to relate their experiences of hope while their infants were in the NICU provides an opportunity for them to voice what might otherwise remain unsaid, thus illuminating what hope is and what, if any, influence the NICU environment has on mothers' experiences of hope.

The effect nurses can have on mothers' hope was uncovered in a phenomenologic study of mothers residing in a live-in unit for parents of hospitalized children (Darbyshire, 1994). The researcher conducted interviews and focus groups with individuals and small groups of parents and/or nurses. While numerous areas of concern were revealed in this study, two aspects are particularly noteworthy: First was the importance parents placed on maintaining hope in order for them to be there for their child. Such hope was affected by an uncertainty as to whose place the pediatric ward was—the parents who were living there or the nurses who worked there? Second, interactions with nurses and other families had a mixed effect on parents' hope. Parents reported being keenly aware of the abilities and caring practices of individual nurses and spoke of hoping for the best nurse to care for their child. In the end, however, the researcher concluded that it was easier for nurses to crush or dash parents' hope than it was for them to strengthen hope: "The briefest comment, the slightest glance, was often enough to send parents' hopes plummeting" (p. 191). While mothers' experience of hope in the NICU is as yet unknown, this study offered some possibilities as to what that experience might be. These findings extended support to the metaphor which likens the mother to a fragile piece of china—delicate, valuable, and easily broken by an insensitive or uncaring action of the nurse (Stern, 1999). Do neonatal nurses realize just how fragile mothers and their hopes are and how destructive one thoughtless statement can be? Are the actions of neonatal nurses figural to

mothers' hope experiences? There are many unanswered questions about hope, but the present study provides a first look at mothers' experiences of hope in the NICU.

A study of the lived experience of hope, framed in the Human Becoming Theory (HBT), was among the first studies employing the Parse research method (Parse, 1990). In this study, ten patients receiving hemodialysis for end-stage renal disease participated in dialogic engagement with the researcher about their experience of hope (Parse, 1990). Verbatim transcripts of the dialogue were read and analyzed according to the Parse method. The essences of hope in the participant's language were extracted, translated into the language of the HBT, formed into propositions, and a structure of hope congruent with the theory formulated. Participants spoke of hope as looking forward to a successful kidney transplant, envisioning life without having to be hooked up to machines, participating in activities which are calming or capable of lifting them out of depression, and trying to carry on a normal everyday life one day at a time. The final theoretical structure of hope for this study was: "Hope is imaging the enabling-limiting of transforming" (p. 16).

An international group of nurse researchers and Parse scholars used the Human Becoming School of Thought (HBSOT) as the foundation for a series of studies on hope. These studies, reported in *Hope: An international human becoming perspective* (Parse, 1999a), sought to answer the question, "What is the structure of the lived experience of hope?" (p. 6). Following Parse's existential-phenomenological research method, thirteen studies of hope were conducted. Included were studies of the lived experience of hope for families living with coronary disease in Australia (Bunkers & Daly, 1999); families members of persons living in a Canadian chronic care facility (Parse, 1999c); persons in Finland (Toikkanen & Muurinen, 1999), Italy (Zanotti & Bournes, 1999), Japan (Takahashi, 1999), and Wales (Pilkington & Millar, 1999); Swedish elders (Willman, 1999); persons in Taiwan living with leprosy (Wang, 1999); Native Americans (Kelley, 1999); persons working with the homeless (Bunkers, 1999); children in families struggling to make a home (Baumann, 1999); women living in a shelter (Cody & Filler, 1999) and American women with children (Allchin-Petardi, 1999). While the research

question and methodology was identical, each study was conducted by different researchers in different locations with different populations. Each study was individually analyzed and a structure of hope elicited. Finally, the structures extracted from each study were synthesized by the principal investigator (Parse) and related back to the principles of the HBT (Parse, 1999b).

Collectively, the studies framed in HBT language and concepts lend support for extant nursing knowledge about hope as an expectation for the future. While all hope studies following Parse's theory and research method involve a translation from the participants' words to language of Parse Science, rich and varied descriptions of hope are found in the reports of this international collection of hope studies. By replicating hope research using the same method in a vast array of people and contexts, a diversity of hope experiences were uncovered. This result supported thoughts about the wide range of possibilities as to what constitutes hope and how hope is experienced.

CHAPTER THREE

METHODS

This study examined the lived experience of hope in mothers of premature infants in the NICU. Nurses have studied hope in patients and families with varying health conditions using both qualitative and quantitative methods. Despite this sizeable body of nursing knowledge, there is a gap in our understanding of hope for childbearing women, particularly those who have given birth to premature infants requiring care in the NICU. This study sought to illuminate the meaning of hope for mothers of premature infants and provide valuable information neonatal nurses need to provide holistic care to families in the NICU. The research design and procedures for participant selection, protection of human subjects, data collection, data analysis, and interpretation are presented in this chapter.

Design

Becoming the mother of a premature infant is a unique experience, one that cannot be adequately described through the exclusive use of quantitative research methods. Likewise, previous research on hope using quantitative methods has not adequately captured the rich detail of the human experience of hope. Nursing, with its philosophy of caring and holistic approach to human care, has turned to qualitative research methods to more fully describe and understand the patient's experience of health and nursing. Many research questions simply cannot be answered by traditional scientific research methods. By implementing qualitative methods, nurses are now able to ask new questions and find answers to questions not amenable to quantitative inquiry.

Existential Phenomenology

Phenomenology, a research method used by nurses to study the human experience, was selected for this study of the lived experience of hope for mothers of premature infants. One of the most prevalent qualitative methods used in nursing, phenomenology is ideally suited to descriptive research with patients about health experiences which affect one's quality of life. Nurses have used phenomenologic methods to study experiences

such as courage (Haase, 1987), suffering (Daly, 1995a, 1995b), or spiritual distress (Smucker, 2002). They have also examined the experience of living with specific health conditions such as diabetes (Mitchell, 1998), chronic pain (Thomas & Briscoe, 2002), or Alzheimer's disease (Parse, 1996). The writings of a cadre of scholars, most notably Husserl (1954/1970, 1962), Heidegger (1927/1962), and Merleau-Ponty (1945/1962), have contributed to existential-phenomenologic philosophy, and numerous approaches to phenomenologic research have been developed. Phenomenologic methods developed by van Kaam (1959, 1966), Giorgi (1970), Colaizzi (1978), van Manen (1984a, 1984b, 1990), Parse (1990), and Thomas and Pollio (2002) have all been used by nurse researchers.

The approach developed by Pollio and Thomas, primarily inspired by the existential-phenomenologic philosophy of Merleau-Ponty (1945/1962), was selected for this study of mothers' hope (Pollio et al., 1997; Thomas & Pollio, 2002). This approach, developed at the University of Tennessee as a method for applied phenomenological research, is ideally suited to the study of the everyday human experiences that are nursing's concern. The structure of this method has four foci: 1) the self, 2) the participant, 3) the text, and 4) the research community. In the initial phase, the self as researcher is the primary focus. The tasks to be completed at this stage include selecting a topic for study and participating in a bracketing interview. Once the study topic has been selected and refined into a researchable question, the researcher engages in a bracketing interview with a member of the phenomenology research interpretive group. Introduced by Husserl (1954/1970, 1962), bracketing is an attempt to suspend or hold in abeyance the researcher's theoretical beliefs, values, and presuppositions in order to remove bias which could be misleading to the participant or result in misinterpretation of the text. Merleau-Ponty (1945/1962) considered bracketing to be an impossible task, and even Husserl admitted that he never achieved complete bracketing. In the Pollio-Thomas method, bracketing is viewed as a way of seeing, and the interview provides the researcher with the opportunity to experience first-hand what it is like to be interviewed about the chosen topic. The bracketing interview, which is transcribed verbatim and

reviewed by the researcher and members of the interpretive group, illuminates the researcher's knowledge and presuppositions about the topic and helps the researcher avoid questions or statements which might lead or unduly influence the participant.

The study participant is the second focus in Pollio-Thomas phenomenologic research method. It is at this point that the researcher meets with the participant in a comfortable, safe environment in which the participant feels free to speak openly about his or her experience. The researcher then engages in a dialogue with the study participant about the phenomenon under investigation. In this pair the participant is seen as the expert, and the researcher—respectful, sensitive, and fully present to the participant and the moment—seeks to understand the experience as lived by the participant. The researcher begins the interview with a pre-determined question and the flow of the dialogue from that point on is controlled by the participant. The researcher uses non-directive questions to encourage the participant to describe his or her experience in as much detail as possible and to clarify meanings in an attempt to fully understand the participant's first-person experience. The focus on the participant continues intermittently during analysis as meanings are clarified and the researcher is confident that the participant's experience has been adequately and accurately captured.

The text becomes the next focus in the study process. The audio taped interviews are transcribed verbatim and carefully reviewed by the researcher to ensure accuracy of the transcription. The text is then read initially by the researcher to achieve a sense of the whole experience related by the participant and to identify meaning units which stand out to him or her in the text. This hermeneutic process is continued in the interpretive group, where the text is read aloud, line by line, and the process of eliciting meanings continues. Next the researcher clusters the meaning units into themes and a tentative thematic structure is proposed. The thematic structure is brought back to the interpretive group for further analysis and review and a structure of the experience is finalized.

The last step in the research process focuses on the research community. At this time research reports are prepared and submitted for publication and research findings are disseminated through professional conferences and other avenues appropriate to the

phenomenon studied.

Procedure

Participant Selection

A purposive sample of study participants was selected from among mothers of premature infants born prior to 33 completed weeks of gestation and admitted to a level II/III NICU. Infants received care in the NICU for a minimum of 1 week, were discharged from the NICU for at least one month, were less than 4 years of age at the time of the interview, and were not currently hospitalized. Participants were limited to mothers for this initial study of hope.

Community sampling techniques (networking, flyers, etc.) were employed to identify potential study participants. All of the mothers resided in the central region of East Tennessee at the time of the study. Some of the infants, however, received NICU care at hospitals located outside of this area. Mothers who were willing and able to engage in dialogue with the researcher about their experience of hope in the NICU were considered for inclusion in this study. Study participants had to be able to speak, hear, and comprehend English, engage in dialogue with the researcher for approximately one hour, and have that dialogue audio taped. Participants were recruited and interviews conducted until the information gathered revealed sufficient continuity of themes among participants. It was anticipated that 8-10 mothers would be needed, however six proved sufficient to elicit a thematic structure of mother' hope in this study (Guest et al., 2006).

Because this study sought to describe mothers' hope as experienced within the most common of NICU situations, mothers with unique circumstances which had the potential to affect their hope experience were excluded from this study. This included surrogate mothers, mothers who relinquished their infants for adoption, and those who became the mother of a premature infant through adoption or foster care. All participants were unknown to the researcher prior to the study and received no specific incentive for participating.

Protection of human subjects

Form B application was made to the University of Tennessee Institutional Review Board and approval obtained prior to recruiting participants for the study. The mothers were informed about the study, including the risks and benefits, before written informed consent was obtained. They were also informed that this research was being conducted in partial fulfillment of the requirements to obtain a PhD in Nursing. Information given to the mothers emphasized the anonymity and confidentiality of all information shared; specifically, mothers were assured that all identifiers would be removed from interview transcripts and pseudonyms used to assure that persons or places could not be specifically identified from research documents and reports.

Mothers were informed of their right to refuse participation in the study and were assured their choice to participate would not be disclosed to their health care providers and would not affect the health care they or their infant received. Mothers were informed of their right to stop at any time during the interview and to withdraw from the study. No untoward effects were anticipated, however mothers were informed the interview could be paused or stopped if she experienced any discomfort or distress during the interview. If the mother experienced extreme distress, plans were in place to stop the interview and, if needed, recommendations made for her to contact her physician, a neonatal parent support group, family clergy, or a mental health professional. No mothers experienced this level of distress during the study.

Study documents which contained identifying information about the participant are being held in confidence by the researcher and were not be shared with other members of the phenomenology research group or the researcher's doctoral dissertation committee. Transcripts, audiotapes, and other study materials were maintained in a locked file in the researcher's office during the study period. The researcher possessed the only key to the file and had sole access to study materials.

Setting

Interviews were conducted in quiet, private locations that were free from distractions. Locations included participants' homes, the University of Tennessee College

of Nursing, public meeting rooms, and private offices.

Procedure

I participated in a bracketing interview with a member of the dissertation committee prior to start of the study. The bracketing interview was transcribed, read, and analyzed in the phenomenology research group directed by Pollio and Thomas at the University of Tennessee, Knoxville College of Nursing (UTKCON) before the first interview with a study participant. Next, I discussed the study with personal and professional contacts in the community, many of whom were eager to assist me in identifying potential study participants. Representatives of the local chapter of the March of Dimes were especially helpful in facilitating contact with potential participants through their *Faces of Hope* program for parents of infants in the NICU.

Once potential study participants were identified, I contacted each mother by phone or email and introduced them to the study. If the mother expressed interest in participating in the study, I explained its purpose in detail, answered any questions she had about the study, and scheduled an appointment for the interview at a mutually convenient time and place. Additional contacts with the mothers were made as needed to confirm the appointments or reschedule when necessary.

Data Collection

I met with each mother in a mutually-agreed upon location, answered any questions she had about the study, and obtained written informed consent. The mother was asked to fill out a demographic data form (see Appendix) while I prepared and tested the recording instruments. The interview was audio taped using a battery-operated cassette tape recorder. I arranged to sit in a comfortable location face to face with the mother. The interview began with the following question: "I would like you to think back to when your baby was in the NICU. Tell me about a specific time when you were aware of hope." Additional questions were asked to clarify meanings, verify understanding, or probe more deeply in order to fully explicate the participant's description of her experience of hope. Phrases such as "tell me more about that?" or "was there another time when you were aware of hope?" were used to help explicate the mother's experience.

Data Analysis

All interview tapes were transcribed verbatim by the researcher and pseudonyms assigned to each person or place mentioned by the participant. This was done to maintain confidentiality and reduce the likelihood that the participant could be identified from the transcripts or subsequent reports. The transcripts were read and analyzed by the researcher, members of the dissertation committee, and members of the phenomenology research interpretive group at the UTKCON. Using the process outlined in Pollio et al. (1997, p. 60) study transcripts were read for meaning units, themes elicited, and an initial structure of the experience of hope was formulated. Feedback and input was solicited from the research group and revisions made to the structure of the experience of hope for mothers of premature infants in the NICU.

Bracketing Interview

As a neonatal nurse I committed almost two decades of my life to caring for high-risk newborns and their families. I took great pride in my ability to provide exceptional care for the tiniest infants and enjoyed that satisfaction of knowing that I was making a difference in the life of countless mothers in the NICU. One encounter with the family of a severely ill infant left an indelible impression on me. This was a child who lived in part due to the meticulous care I had provided, but his prognosis was poor and the long-term outlook appeared bleak. I stood shoulder to shoulder with the neonatologist and nurse practitioner in encouraging the parents not to withdraw life-saving support, but to not engage in further aggressive interventions and surgeries. It was the only time in my 17 years of practice a family requested that I not care for their child any more and I was stunned. After years of reflection I realized that I had committed the unthinkable act of attempting to remove the hope these parents had so bravely clung to.

Over the years I witnessed many things in the NICU. I saw eager physicians paint what I believed to be excessively rosy pictures for families of critically-ill premature infants and experienced the angst of hope vs. false hope and honesty vs. sensitivity in communications with parents. I observed countless mothers as they watched horrible

things happen to their precious children and I wondered how they survived the nightmare. I also saw the small sparks of joy that appeared on the faces on these mothers when I went above and beyond the norm to see to it that they got to hold their babies skin-to-skin, or touch them, or feed them, or do other things that many of my colleagues would not allow or take the extra time to do. Do those little things made a difference? Is it hope that gets mothers through the long days and nights in the NICU? Was it hope that I was nurturing with all the little extras I was doing? Is there something more than nurses can do to make things better for moms? I think the answer is yes but only the mothers know for sure. That's why I asked them to tell me about their experiences of hope.

CHAPTER FOUR

FINDINGS

Study interviews were conducted over a period of five months from October, 2006 to February, 2007. Six mothers, ranging in age from 29-36 years, were interviewed about their experiences of hope in the NICU. All the mothers were white, married, and had college educations—four in health-related fields. Stated religious preferences were Buddhist (1), Catholic (1), Christian (3), and none (1). Half of the mothers attended some type of religious service at least monthly while the other half seldom if ever engaged in such activities. It was the first pregnancy for one mother and the second for 3 more. It was the third or fourth pregnancy for each of the remaining two mothers in the study. Five of the mothers experienced preterm labor while two had premature rupture of membranes. Other complications of pregnancy included bleeding (2), high blood pressure/toxemia (1), incompetent cervix with cerclage placement (1), and infertility (1). Two mothers gave birth to twins, one at 23 ½ weeks and the other at 29 weeks.

Premature infants born to mothers in the study included 5 males and 3 females, ranging in gestational age from 23 ½ to 31 weeks at birth. They received care in one Level II and three Level III NICUs located in two states in the southeastern United States. All of the infants were critically ill, requiring mechanical ventilation, oxygen, intravenous medications and fluids, and tube feedings during some portion of their stay in the NICU. Additional interventions included blood transfusions (4), chest tubes (2), and surgery (PDA ligation-1, hernia repair-1, laser eye surgery-3, and gastrostomy tube placement-1). The length of NICU hospitalization extended from 5 weeks to 4 months. Ten months to 2 ½ years elapsed from the time the infants were born until the mothers were interviewed for the study.

Thematic Structure

The experience of hope for mothers in the NICU was complex and multifaceted. After many careful readings by the researcher and an the interpretive group, the thematic structure of hope emerged from the text of the transcripts. This structure is presented in

Figure 1. The contextual ground from which the mothers' experience of hope emerged is the World of the NICU. The most salient attributes of this world included uncertainty, time, powerlessness, and others. There were three major facets in the mothers' experience of hope: (1) the hope mothers had for their infants, (2) their own personal need for hope, and (3) hope as experienced in relationships with others, including NICU health care professionals, family members, and friends. In addition, there was a continuous interplay among the three facets of hope. Hope is represented by a three-sided pyramid with each side standing for one facet of hope and the equilateral triangle on the top suggestive of the inseparable nature of hope (ie., the mother, infant, and others co-constitute the experience of hope). The diagonal line reflects the passage of time or the journey which the mother/infant dyad take from birth and admission to the NICU until discharge. The pyramid is precariously perched on its apex, symbolic of the uncertainty that is all pervasive in the NICU. In an environment where uncertainty is ever present, the facets of hope are in constant motion, tilting to one side or another as conditions change over time. The constant motion reflects the instability of this world and the unequal balance of power that exists in this environment.

The World of the NICU: "A New Place for Me to Be"

For mothers anticipating the birth of a healthy newborn in a hospital or birthing center, having your infant born prematurely and admitted to the NICU is an experience that almost defies description. The world of the NICU is a very different place from the well baby nursery. With little or no warning mothers suddenly find themselves thrown into an unfamiliar place where they are forced to deal with unfamiliar people, their infants have a litany of unfamiliar problems and they find themselves struggling to mother their precious child in a place where the expectations for this role are likewise unfamiliar. Mothers in the study universally described their initial foray into the NICU as "overwhelming." One mother spoke of her reluctance to go to the NICU to visit her son in the first few days after his birth: "I just wasn't comfortable, it was like a new place for me to be.... It was like... going to a party and you don't know anybody.... I felt really alone

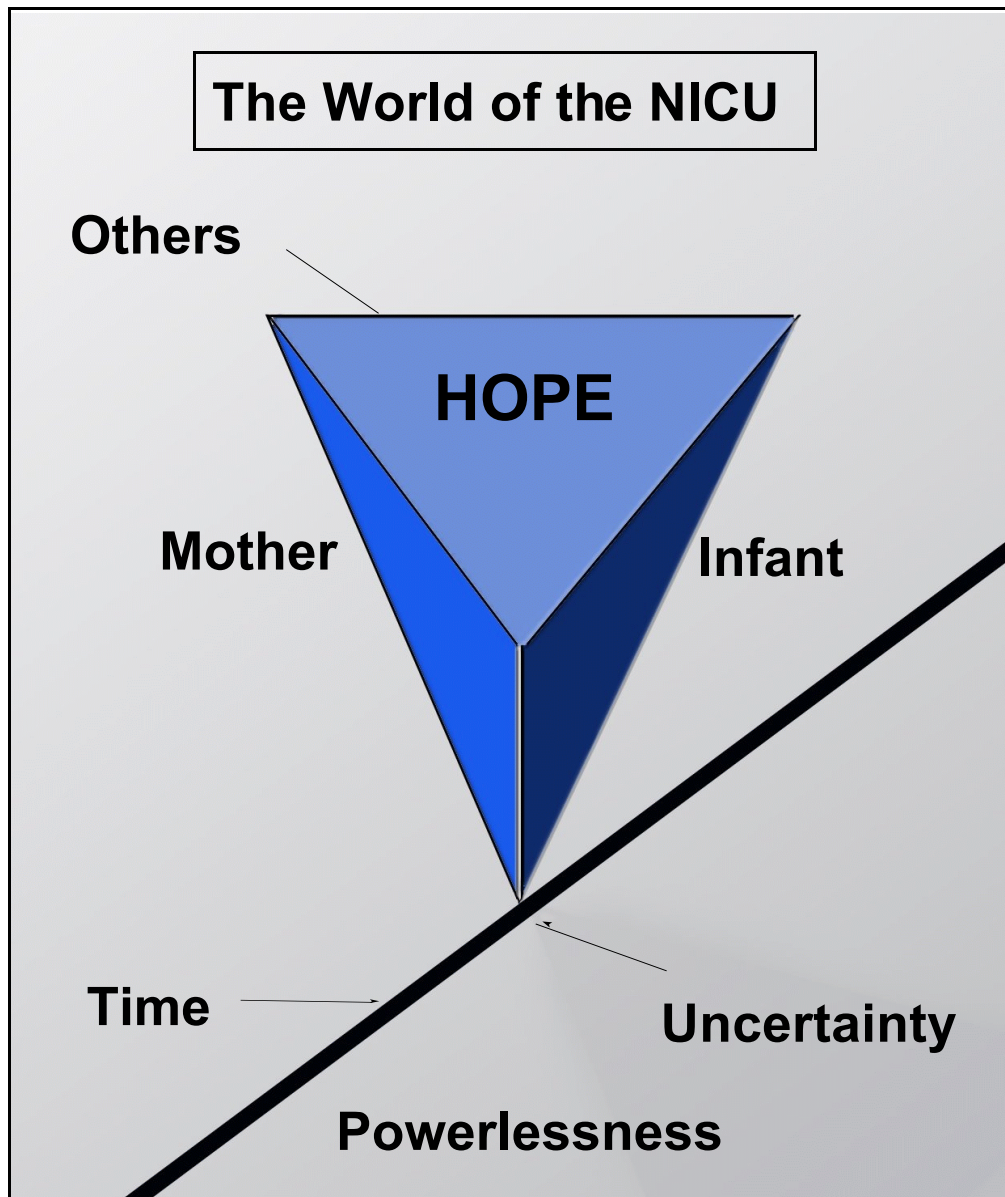


Figure 1. Thematic Structure of Mothers' Hope in the NICU

The pyramid symbolizes the three facets of hope in the NICU: Infant, Mother, and Others. The slanted line represents the passing of Time in the NICU from admission to discharge. The contact point of the pyramid with the line represents the pivotal relationship that Uncertainty has on Hope in the NICU. The inverted position of the pyramid is suggestive of the precarious nature of maintaining hope in a constantly changing environment which the mother is powerless to change. Graphic courtesy of Diana L. Cooper.

in the whole thing.”

In contemporary American society newborns are supposed to be born in a place where there are pretty cribs with cuddly blankets, dim lights, hushed voices, soothing music, and the “baby” scents of lotions and powders. Hospitals and birthing centers go to great lengths to create this welcoming environment for uncomplicated births and healthy newborns. But give birth to a premature infant and the environment changes drastically. In most NICUs bright lights are on day and night. The staccato of monitors alarming above the constant hiss of ventilators and hum of incubators is interrupted only by the talking of NICU personnel who don’t seem to be familiar with the idea of speaking softly. Even the smell of the NICU was distinctive to mothers in the study. They spoke of the NICU environment in less than pleasant terms.

Fran, the mother of a 27 ½ week gestation son recalled her first visit to the NICU like this:

It was just so *big*. And I remember, you know, at first feeling so completely overwhelmed.... We were in the last pod so we passed every single pod to get to Frank and just baby after baby after baby. Machines beeping— I mean it was just all you would hear and it, it felt so overwhelming and crazy at first.... It was big, ...bright, sterile, it smells....

Fran was not the only one put off by the distinct smell of the NICU. Emily, the mother of 29 week twins, remembered it clearly as well: “And to this day the smell— not a bad smell, just a *smell*.... Cleansers and babies and whatever all mixed up. But it’s just this distinct NICU smell.” She also felt overwhelmed by the unfamiliar world of the NICU:

It’s just all the beeping and the strange equipment and all that. It’s, it’s just *very* overwhelming. And it’s not what you expected or dreamed of, I mean nobody wants that you know. You have a vision of what your birth’s going to be and that wasn’t it.

Carrie, the mother of a 30 week gestation son, found the noise level in the NICU to be the most distressing: “It was *loud*. So many, um, just all the beeping and the people

talking....” While the mothers in the study admitted to getting used to bright lights, noises and smells of the NICU, they still viewed the NICU environment as a negative place to be. The negative nature of the NICU environment made hope difficult to maintain. According to Emily, “it just made...a stressful time a little more stressful.” Carrie found it took a lot of work “to stay positive and be happy [in] this negative surrounding..” She likened being in the NICU to floating on turbulent waters: “because it’s hard to stay afloat.... It’s kind of like hopping [on] your life preserver or something.” It’s hard to maintain that delicate balance when you have a premature infant in the NICU.

Uncertainty

When you have a premature infant in the NICU one thing is for certain— nothing is ever truly certain in the NICU. Uncertainty was pivotal in the Mother’s experience of hope in the NICU. Not knowing what to expect or when was a constant challenge. Even when mothers had been informed of all the things that could possibly happen, what actually happened was unpredictable. Denise, the mother of 23 ½ weeks gestation twins referred to this state of uncertainty as “suspended limbo.” She said, “I never could deal with uncertainty very well. Throw anything you have at me, just let me know it’s coming.” But of course it’s impossible to know what’s coming,

Not knowing what would happen or when, even if your child would live or die let alone what the long-term outcome would be left mothers searching for something, *anything* they could depend on in this state of constant flux. And when they didn’t know where to turn or what to do, that’s when they turned to hope to get them through the experience. After she recounted an incident that would shake the soul of even the most experienced of neonatal nurses, I asked one mother the question, “why hope at this point?” This was her poignant reply:

What else did we have? We had no statistics. We had no information. 23 weeker preemies—nobody knew anything, and still don’t. I mean we knew all the things that could and probably would go wrong but nobody could tell us what was gonna go right. That’s all we had. That’s all we had, that and faith that somehow, some way, somewhere God was going to take care

of this.

So when there was nothing else left to hold on to, this mother held fast to hope and refused to let go. In this situation hope filled in the gap left by the uncertainty of not knowing what was going to happen.

At times mothers wanted to have hope, but were uncertain what to hope for as they keenly felt the conflict between what they wanted and what was best for their infant. Caught in the unenviable position of not knowing what to hope for, Abby, the mother of a 26 week gestation son, turned to prayer:

I'm not a religious person and I don't really make it a habit to pray and I remember not bargaining and not knowing what to pray for when I just I don't think at the time I wanted to have hope because it's hard and I felt like I needed to pray for something and I just didn't know what to pray for. I didn't know whether I wanted my child to live or die.... It wasn't a lack of hope and it wasn't a whole lot of hope it was just, was just right in the middle.... I was so worried about my child's quality of life I didn't know that I wanted to hope for him to live and then have this... very complicated medical life and not have any quality to it that I could see. I didn't want to *have* that hope and wish for him and at the same time you know, I didn't want to wish for my child to die.

From this example it is clear that hope is not something all mothers possess. Mothers are not automatically endowed with it upon becoming pregnant or giving birth; rather it is something that has the potential to develop over time.

Time

Time was also salient in mothers' experiences of hope of the NICU. The uncertainty of not knowing when something would happen was as trying to mothers as not knowing what would happen. When uncertainty was at its most extreme the hands of time turned excruciatingly slow for mothers in the study. They talked not only in days and weeks, but in hours and minutes—the slower the clock seemed to tick, the greater seemed to be the mothers' need for hope. "That would probably be the beginning of hope" said

one mother. “Hour by hour, you know, minute by minute, hour by hour, day by day.” Whether it was waiting for the phone to ring with bad news or waiting for the good news that it was time to their infants home, waiting was hard on the mothers. For Fran the long wait to go home seemed to last forever:

We saw baby after baby after baby coming in and leaving, coming in and leaving. And there we sat. And every time a baby would leave the nurses would come over and say, “your day is coming, your day is coming.” And we were are you sure? I don’t know... it felt like forever.

Even the day-to-day routines of the NICU were driven by the clock. Mothers quickly learned to abide scheduled times for feeding, holding, and diaper changes. At times the regimented schedule of the NICU impinged on mothers’ sense of freedom, but there was some relief to be had routines such as using the electric breast pump. Abby related: “During a very stressful time every three hours I sat down for 15 minutes and pumped... and that’s what got me through.” It was surprising to hear how spending a few minutes alone in a quiet room with nothing more than her own thoughts and a breast pump seemed to nurture hope.

Powerlessness

Mothers in the study used language that communicated the powerlessness they felt in the world of the NICU. From the “overwhelmed” feelings of the first week in the “big” NICU one can envision just how small and vulnerable the mothers felt in this strange place. Clearly the NICU was a place under the control of the doctors and nurses and the mothers quickly learned to adjust to the rules and restrictions. They rarely questioned the restrictions, dismissing them as something they couldn’t change. Instead mothers talked about feeling helpless when they couldn’t touch or hold their infant until after the nurse had given them permission to do so. Beth reflected on these feelings: “And you feel sort of helpless because you know..., they don’t let you hold her very often or at least not for very long...” Mothers liked having primary nurses, but were disappointed when their primary nurses weren’t assigned to care for their infants: “Although we found out once they signed up somehow they never seemed to get our baby again, which was kind of

disappointing.”

Theme 1: Hope and the Baby

Mothers' experiences of hope were directly influenced by what was happening with their infants. When asked to recall a time in the NICU when she was aware of hope, each mother told of a salient event from which an awareness of hope emerged. These events usually did not take place in the early hours or days after admission to the NICU, rather they happened weeks later. Powerful emotions were attached to the events spoken of by the mothers; many addressed the ultimate uncertainty—questions of life and death.

Discouraging Events

In perhaps the most compelling of these narratives Denise talked about her son who had acquired a coagulase negative *Staphylococcus* infection and was severely septic:

We had shown up, it was December 14th, Tuesday night. We had shown up, we had already made him a *do not resuscitate*, had shown up to prepare for the death vigil, to say goodbye. We were making funeral arrangements or planning the funeral, how did we want this to be because we knew he was going to die *that night*. It was, there was no hope. It was over. We were just waiting for it to happen, and weren't even sure if we were going to make it to the hospital in time to be there when he died. He made it through the shift. ...When we walked in that night he was blue, he was cold,...When we walked in the next morning he was pink....That was probably the first time that I was truly aware of hope. That we were actually going to get through this. Because up to that point, for the 3 weeks up to that point we were just waiting for the other shoe to drop.

In this situation the mother interpreted the dramatic change from blue and cold to pink as an indication of her son's will to live and her cue to hope, something she had not “allowed” herself before. Her rationale for having hope at that point was simple:

When there is nothing else that's all you've got, and we didn't even have that for the first 3 weeks (pause), or I would not allow myself to experience it.... I knew what my chances were.... We... just kept waiting

for the other shoe to drop... I knew it was going to drop sometime, it was just a question of when. When were they going to get tired? When were they going to give up the fight you know? You know, how long can this go on? She was 1 (lb), 3 (oz); he was 1-5. They were 23 weekers, they had nubs for lungs. You know, what could you possibly expect from half-baked? So I wouldn't even allow myself to hope until I saw, until we saw Devin turn around.

Denise was not the only mother whose hope surfaced after a frightening experience with her child. Emily was holding one of her twins when she had the scare of her life:

Evan was a week and a half old maybe, not very old, and it was... maybe the second time I got to hold him. He still had IVs and all...the cables and cords and everything... and we had taken him out and I was holding him. And I hadn't been holding him very long, monitors started going off and you know... [he] turned blue right there... bigger than life he turned blue.

The nurse calmly resuscitated the baby and returned him to his bed. Emily continued:

So we put him back in there and I was just sitting in the chair. And she just looked at me and she said "Are you OK?" And I said "*No*, I am *not* OK. I don't think I'm ever going to be OK *again*!" Having seen your child do that!

Evan required high-frequency ventilation and chest tubes during the first several days of his life but Emily, recovering from a C-section in the hospital across the street, had not been well enough to visit yet and had not been a witness to those aggressive interventions. It wasn't until much later when her son stopped breathing and turned blue in her lap that the possibility of "something bad" happening became real to her. And it was in that moment that she felt the need for hope.

It is not uncommon for premature infants to have episodes of apnea and bradycardia due to immature development of the nervous system. Nevertheless, these episodes were terrifying to mothers, especially if they occurred while the mother was

holding her infant. Fran related this experience:

He had [on] a blue hat and a little blue outfit and a blue blanket... and I'm holding him and I looked down at him and thought gosh, he looks kind of his outfit. And I look back and the alarm goes off and he was down to about 38. Oooh! And the nurses are all just running over there and it scared me half to death.... I just remember feeling like my heart, you know when you get scared and you feel like your heart's going to stop and you feel like prickles going through you? That's what it was like.... He just looked like a little Smurf!

Like Emily, Fran acknowledged that her son was fine after the nurses swiftly intervened, but the experience left her feeling anything but fine: "He's fine you know;... I'm not!" The unpredictability of things like apnea and the constant fluctuation between up and down, better and worse, progress and no progress was hard for all mothers in the study to endure.

Sometimes discovering hope was the consequence of a temporary set-back in the infant's progress. Such was the case for Carrie, a nutritionist whose son suddenly stopped tolerating his feedings for reasons that could not be explained.

He was doing really well and then he stopped tolerating his feedings. So then we had to cut back and that was the only thing really keeping him from going forward is that he just wasn't tolerating his feeds....I was like OK, I've got to look at the positives on all this....all the good things, everything that went well with him... because they said two steps forward, one step back, this was just another hump in the road, you know. I knew we could get through it. I just kept looking at the positives, you know, prayed a lot.... Most babies are going to do this....Two step[s] forward is good, but if something happens to set them back a little bit it's not the end of it you know, they still can pull through.

So even when things weren't progressing as they wanted, mothers found a way to get through the uncertainty of "normal preemie" behavior by thinking positively and hanging

on to hope.

Encouraging Events

Hope did not always present itself as the result of a negative experience, mothers found hope in positive things too, such as when their preemie attained a significant developmental milestone. For Abby that milestone came when her son finally came off the ventilator after aggressive supportive interventions and numerous failed attempts:

It was from ventilator, conventional to oscillating, for seven weeks and then when he was done with it he was done.... He was done and he didn't have to go back on the ventilator ever. And that, that was very telling for me. That's when he told me that he was gonna pull through, that he was ready, it's time... and I took a lot of hope in that.

Having already spent 2 months in the NICU with Alexander, she needed that signal from him to feel confident that he would live. Shortly after coming off the ventilator her son was transferred to the intermediate care nursery:

As he started to get better and moved from the intensive care nursery to the intermediate care nursery, then I started to have some hope....I remember specifically talking to the nurses and saying you know, we're going to start cleaning up the room for the nursery now. And *that's* when I started having some hope for him and hoping that he would have a good life and there was going to be, you know, light at the end of the tunnel.

Abby began to have hope when her son was only half-way through his stay in the hospital, but for Fran the signal to hope came close to discharge on the day her son first came off oxygen:

After being in the hospital for 50 or so days that was the first time that he had been off of any sort of oxygen and that was the first time that we thought hey, we're actually going to make it home. And we were hopeful for our homecoming.

In this situation hope was all about the baby being well enough to go home and it wasn't until that oxygen cannula was gone from her son's face that Fran captured that first

glimmer of hope.

Coming off respiratory support was only one of the major milestones mothers looked to for reassurance that their children were growing and improving. The daily ritual of weighing the baby was closely monitored and served as the leading indicator of progress. As one mother noted, the achievement of each milestone was cause for celebration:

We would make such a big deal when he would get to all the new things. Like when he got to a new pound. He was 2 ½ pounds when he was born. Three pounds—I thought we were gonna, you know, tear the hospital down with a party. I mean we were so excited. And then four pounds (laughs), every night for several nights we would stay at the hospital while they were doing his weight and stuff like that, so that we could take a picture of the scale when it said he was at the new pound. It would always seem that he would gain, gain, gain, gain and then he would get right at the pound and he would go down like he was playing a trick on us or something.

Conversely, failure to maintain consistent progress reflected in such things as decreased ventilatory support or oxygen requirements or increased feeding volumes was a source of great frustration to mothers. Even so, keeping a close eye on their infant helped mothers maintain hope in the face of adversity:

I don't know, something just kept me at peace and calm because I had him there. I could watch him and see how he progressed, how he was growing, how he was gaining weight,...how he just seemed happy and he didn't seem too stressed.

Mothers engaged in various activities to track the progress of their infants, thus nurturing hope. Frequent phone calls and almost daily visits were the norm for mothers in the study. Several mothers talked about the importance of journaling, baby books, scrapbooks, and taking photographs to document growth and improvement. One mother set up her own internet blog, posting pictures and daily updates. She recalled how comparing pictures over the days and weeks helped her to visualize her son's progress at

a time when she had difficulty seeing that growth in person.

Theme 2: Hope and Others

Physicians, nurses, and other health care professionals as well as family members and friends profoundly influenced mothers' experiences of hope in the NICU.

Interpersonal relationships in a time of crisis can be difficult and mothers' feelings were quite sensitive at a time when the life of her newborn was in jeopardy. Such circumstances made it difficult for others to act in a manner that would be perceived as supportive of mothers' hope.

NICU Professionals

The mothers in the study spoke of NICU professionals who supported their hope in glowing terms. For the most part the mothers were pleased with the doctors and nurses. They were confident in the care they received and felt comfortable leaving the NICU knowing their infants were in competent hands. Denise talked about her feelings of leaving the hospital without her twins:

I did not leave the hospital when I was discharged with a sense of loss or leaving something behind. I was really OK with it. I would go and visit them in the unit and I wouldn't cry on my way home. I was fine leaving the hospital without them. It, it actually gave me comfort to know they were there even though I wasn't because what they were getting there was far better than what I could do. I didn't know how to do that. I knew what they were doing and why they were doing it, but I couldn't do it myself. And they were getting [care] 24/7 and it really did not bother me. It did give me a sense of comfort.

When Emily became ill and couldn't visit for a few days, frequent communications with the nurses and confidence in the care they were providing her twins helped her get through some difficult days: "I talked to the nurses constantly, you know, and had no doubt that they were being completely cared for." Beth, the mother of a 31 week gestation daughter was buoyed in "knowing that these nurses had done this for

hundreds and hundreds of babies....They were so capable.”

While competency was important to mothers, a caring demeanor and positive, professional attitude went a long way to support mothers’ hope. The doctors and nurses were expected to be positive and hopeful in their communications with mothers. One mother talked about how the positive attitude of her doctors affected her:

My doctors were very, very positive, very supportive. I can not say enough good things about them. I think that made a huge impact on me...their attitude really helped me.

Mothers also expected difficult or otherwise negative information to be delivered in a manner that preserved hope. When professionals failed to communicate in a positive or hopeful manner, mothers took offense. Fran expressed her feelings about a negative encounter with a physician shortly after she was transferred to a regional referral center in preterm labor:

I remember the one doctor coming in saying... *if* your son survives at 27 weeks gestation the issues that you could be facing with him are so much that it might be better off for you if he didn’t live at all.(long pause) And you don’t tell people that, I don’t care how bad it’s looking, you don’t tell someone oh it probably better if your son just dies. That’s absurd!... I thought that was rude.

Mothers also were pleased when nurses volunteered to be their primary nurse. Continuity of caregivers, especially having the primary nurses actually assigned to care for their infants, was figural to all the mothers in the study. A mutual friend notified a NICU nurse when Beth’s daughter was admitted to the unit: “when she found out she immediately went over and signed herself up for our baby so she was like our guardian angel.” But her joy in having primary nurses was short-lived: “Although we found out once they signed up somehow they never seemed to get our baby again, which was kind of disappointing.”

It didn’t take long for mothers to appreciate the qualities of good nurses, the ones who gave great care and supported their hope in lots of little ways. Emily rehearsed the

attributes of the good nurse who cared for her son while he was on the jet ventilator with a chest tube:

She was called in specifically to be his nurse. She was his nurse for the first couple of days and she was there when I went in the first time. And I remember...how calm she was, how nice she was. She explained everything, told me what everything was. Yes, you can touch him, do this and that.

She continued to describe good nurses as: “the ones that maybe went the extra step, that went the extra mile, the little extra are the ones who made the biggest impact.” And perhaps most importantly, the good nurse was the one “that made me feel like they are my children, not theirs.”

Good nurses took the time to explain what was going on with the baby in detail, supported breastfeeding, and strongly encouraged mothers to take an active part in caring for their infant. It was clear that the most important thing nurses could do to support hope was to give mothers the liberty to truly *mother* their child.

Mothers acknowledged the good nurses who supported their hope while providing excellent care, but it was the nurse with a negative attitude or the negative encounter with a nurse that left deep and lasting scars. It was the “bad” nurse that was most readily recalled within the context of hope in the NICU. When asked to talk more about having different nurses, Beth was rather generous in her appraisal:

Some of them you really like and then there were a couple we just didn't like, didn't like very much at all. My husband...had more animosity towards some of them, one in particular.... She just seemed bitter and didn't need to be there I didn't think—like she was over the job.

Carrie didn't fare so well in her encounter with a nurse with an attitude. The destructive impact of a single negative encounter was profound: “You're trying to stay positive and be happy...and you get that one negative comment and it really affects you like ten-fold.” She went on to say:

How important it is for the nurses to think about how they're affecting people every single day. If they're having a bad day don't take it out on the patients... 'cause they don't know that you're having a bad day. They think it's a personal thing. They take everything [personally]..., they're a little more sensitive than they would normally be.

She was so distraught after an experience with one nurse Emily requested that the nurse never be assigned to care for her children again. When I asked what the nurse did, she replied:

She was just kind of rough....just really rough in just moving her around, in turning her.... She was changing tape on her face from her tube...and she ended up taking the tape off and it left just a horrible place on her face.

Failing to be gentle with the infant wasn't the only reason for this mother's displeasure:

When I came in that day she didn't hardly even acknowledge that I was there, didn't really tell me what was going on, didn't give me information; just went about doing her work as if I was not the child's mother, you know, like I was just a bystander.... She acted like I was more of a nuisance. Like I was kind of in her way of her doing her job than the mother of the child she was caring for.... I just didn't like it.

Few things crushed the tender hopes and feelings of mothers more than being neglected by nurses. Worse yet were the rude or insensitive nurses who prioritized their own needs above those of the mother. Their cutting remarks were devastating. The pain of such an experience was still fresh on the mind of one mother whose nurse "yelled" at her over breast milk:

She said I had too much milk in the refrigerator and I needed to stop bringing milk in.... It wasn't that I was bringing the milk from home, I was pumping it there and leaving it... I had tons at home still too. So just her negativity about that, I was like no wonder these nursery moms stop breastfeeding if this is what they're gonna get.... That negativity from that one woman, that one nurse, like stomped on all the positive energy from

everybody else who said “Oh it’s liquid gold, we need as much you can get...” you can stack the freezer full if you need to, we’ll make more room.

She continued:

When she first said that to me I was shocked and I wanted to cry. I was just hurt, it was like my feelings were so hurt.... I was holding back tears and I didn’t want her to see me cry.

The mother acknowledged that this nurse was a “good enough” nurse and “she cared about the baby and wanted to take care of the baby” but the nurse was on a “power trip” and need to keep the mother in her place: “I was taking up too much space.”

A couple of mothers in the study voiced strong opinions about having to put up with nurses who had “bad attitudes” or who brought their personal problems to work with them, thus compromising their ability to provide care. “Once they walk through the door, they need to leave their own problems at home...if they can’t do that, they should be here” opined one mother.

Nurses were expected to behave in a caring, professional manner at all times. Bringing personal issues to work was viewed as conflicting with the nurses’ ability to devote sufficient attention to patients and families. Mothers recognized that nurses had stressful, demanding jobs and were very busy, but this was no excuse for failing to acknowledge the mother or attend to her needs. Good nurses kept mothers well-informed and encouraged active involvement in caregiving. They welcomed other family members and friends to the NICU, were flexible with schedules and open to mothers’ individual needs and requests. In short, good nurses went out of their way to do the “little things” that “made a huge impact” on mothers’ experiences of hope in the NICU.

Friends and Family

Mothers in the study depended on the support and encouragement of family members and friends to help them get through the experience of having a premature infant. Each person had a unique role to play in succoring the mother from labor and delivery until the infant was discharged home from the NICU. Several mothers who had planned for “natural” childbirthing experiences in alternative birthing environments

spoke of the comfort they felt by having an “emergency” doula available to them during the terrifying hours of labor and delivery. After delivery, doulas accompanied the fathers into the NICU and were extremely helpful in providing information and encouragement in that first encounter with their son or daughter.

Grandparents were often life savers as mothers tried to heal from C-sections, deal with the shock of having a preemie, and cope with older siblings at home. Emily talked of the peace she felt knowing her parents were visiting her twins every day during the time she was sick with an infection and could not be there herself. Fran was appreciative of the many hours her father simply sat with her at the bedside of her son. When Carrie was “numb” from the experience of her unexpected early delivery and reluctant to make the long trek down the hall to the NICU, it was her mother that gently prodded her to find the courage to go see her son. Emily reflected on the support she received from her extended family:

It’s so difficult, even in the best of circumstances....You know you’re driving and trying to deal with your family at home and your kid’s somewhere else— I mean it’s just stressful in the *best* of circumstances and I think not having a good family support unit would be awful.... I had good family support... good church family, knew there were lots of prayers, lots of people thinking about us. If we needed anything I knew there were a handful of people I could go to immediately for anything.... I think going through the NICU... alone or without some kind of support, or without hope for a good outcome— I don’t see how you could physically survive that, I really don’t.

Knowing that she was not alone was of vital importance to the mothers’ experience of hope.

Little acts of kindness like telephone calls and e-mails or flowers and gift baskets were genuinely appreciated and helped acknowledge the birth of a new member of the family. Beth was the grateful recipient of one such gift:

A friend sent a diaper bag full of, you know, the NICU survival kit with lotion and gum, all kind[s]... of baby stuff and little preemie clothes and a book and it was just great! And she had said someone had done it for her when her daughter was born. It was like one of those pay it forward things.

Carrie talked about a scrapbooking workshop that was offered during her time in the NICU and Fran mentioned a premature baby book that she was given. Both felt creating these keepsakes helped them to pass the time and better deal with the uncertainty of being in the NICU.

While friends and family were generally supportive of mother's hope, conflicts did arise from time to time. For some mothers in the study it was difficult to feel supported by their husbands who reacted differently to having a critically-ill premature infant in the NICU. According to these mothers, in the face of uncertainty their husbands were more likely to maintain emotional distance or avoid feelings of hope. While understanding of this behavior, the differences were hard for mothers. As one mother put it, "it just made a stressful time a little more stressful."

Theme 3: Hope and the Mother

The hope mothers had for their infants and their own personal hope needs were deeply intertwined. Of the three facets of hope in the NICU, mothers' hope was the most fragile. The slightest change in the baby, the NICU environment, or others could send mothers' hopes soaring or crashing down. While mothers in the study reported having positive feelings or an overall sense of optimism throughout their stay in the NICU, hope was not always present. Having hope took effort on the mothers' part.

Lack of Knowledge/Uncertainty

Mothers' hope was challenged by the unknown. The uncertainty of being in the unfamiliar environment of the NICU and not knowing anything about prematurity limited mothers' ability to have hope. They sought information from multiple sources including, but not limited to NICU professionals, books and other media, and others with previous experience having a premature infant in the NICU. Beth talked about how searching out

information from books helped her find hope:

We read a lot. We're researcher type people so that was helpful to have books to read about what other people had done and knowing that a lot of people had it worse off you know, that their babies were a lot sicker, maybe born because something was wrong with them. We really just felt very lucky.

She explained why reading books about premature infants were so helpful:

Because alone with my own thoughts things sounded more dire than they were, like explaining the hemorrhage– the little tiny hemorrhage– and she had a PDA (patent ductus arteriosus) as well. And when they talk about it it's scary... and then to go back to our books...because it explained everything the doctors had said but you can read it and digest it easier and read it again if you need to... You know, you hear the words “hemorrhage” and your baby in one sentence all, you know, parts of you stop listening... and start going off on these flights of fancy that are not fanciful...

Books helped lessen some of the untoward effects of uncertainty by educating parents about the many aspects of prematurity. They helped mothers know what to expect, what things might happen, and what was normal for a preemie. Emily valued the information gleaned from the books she read:

I got a wonderful book that I read and I think it made a huge difference in explaining a lot of the medical stuff--what to expect, things that could happen, things that could go wrong. But at least I knew ahead of time what might could happen.

Like Emily, Fran also benefitted from a book she received:

Their volunteer association... gave us the preemie book, the really fat, thick preemie book which I call my preemie bible because there's everything in the world in there and I still reference it to this day.

Several mothers in the study mentioned the importance of having access to information about prematurity outside the NICU. Denise used the internet to search for answers to questions she had, especially when preparing to take her twins home on oxygen, monitors, and multiple medications. Fran found that networking on the internet, especially through her blog, was a wonderful way to connect with others and share her experience. The feedback she received from blogging really buoyed her sense of hope and helped her to know just how many people cared:

Just constantly, our messages and emails with people wanting to make sure he was OK.... That felt good, I mean we knew that people all over the world were praying for *our* little boy and that made us feel great.

Despite being inextricably linked, mothers' hopes were not always in unison with hope for the infant. Conflicting desires were a source of anguish for mothers, especially when there were difficult choices to be made. They agonized over decisions where they felt forced to choose between what was best for the child and what was best for themselves. No choice was more agonizing than the decision to resuscitate an infant born at the edge of viability. Abby was tearful as she talked about being in labor at 26 weeks gestation and after speaking with the neonatologist, having to make that most difficult of all decisions:

I had a really hard time with the idea that... because they have to resuscitate the baby, you have to either decide you're gonna go the course at the time of birth or you know, decide you're just going to hold the baby and let him go. And that's kind of difficult for me to get.... I said "I understand, go ahead and do what you have to do, but if he tries to die let him." Because from the very, very beginning I didn't want him to live if he wasn't going to have a quality of life.

She lamented:

Life's so fragile, especially those first few weeks.... And you get a phone call and the blood gas came back and it's so off the wall... a pH that's incompatible with life and you wonder...if it's incompatible with life and

when they get it resolved, what then? It's just so hard to make decisions... it makes it hard to hope for a child, my child when he's so tiny and you're caught in the middle and it's really hard to have hope... and you get to where I hope, *I hope that my child will be OK.*

As if making the decision to resuscitate wasn't hard enough, having to defend your decision to others made the situation even more difficult. Denise found herself having to do just that when a new rotation of nurses came on shift. After lengthy discussions with the neonatologists Denise, a nurse herself, and her husband requested a Do Not Resuscitate (DNR) order for their son Devin who had been comatose and near death for several days. She was quite animated as she replayed the scene for me:

The next thing you know I've got this cute little new nurse, "Well Mrs. D, we see here that you made your son a DNR. We're really kind of confused by that, could you...?" Why the kid is fine, why would you do something like that? I about hit the roof. I about hit the roof. Excuse me, did you not get a report? "Well of course we got report." Well obviously not a very good one. Have a seat and let me give it to you.... This new rotation of nurses...were not the twins' primary nurses, these nurses were new and I guess did not read the chart, did not get a very good report, I don't know what happened. The next thing you know I've got social services being consulted because of Mrs. D's inappropriate DNR order. Some of those nurses don't like me very much.... I gave them more of a report than they ever wanted. I can give a damn good report when I want to.

Ineffective nurse-to-nurse communications persisted and Denise continued to receive grief from NICU nurses over the DNR order. Relief came after a conversation with the neonatologist:

A couple days after that I was visiting and I brought that up to Dr. S. "OK look, this has been questioned, what do I do?" And he just looked at me and said "Oh these kids aren't going to die. He's fine. He's gonna make it. He went through that. He's gonna make it." I mean just dead straight, eye

contact, “He’s not gonna die, not now. He’s gonna make it.” That would probably be the other instance or recognition of hope. Of Oh my God, we’re going to make it through this. We’re going to make it through this!

The frank language and brutal honesty on the part of the neonatologist addressed the uncertainty of the situation and offered enormous hope. As Denise put it, “it was just what I needed to hear.” In fact, she was shocked by what she heard:

And I just kind of looked at him like you’re kidding? And he said “no, he’s strong, he’s going to make it. If he was gonna die he would have done it by now and he hasn’t. In fact he’s going to get sick, we’re going to have issues, we’re going to have problems. He’s not out of the woods yet, but he’s going to make it”. And from then on it really, hope wasn’t even, I didn’t even think about it any more. It was just there. It wasn’t even hope, it was knowledge.... I don’t know, I mean. It’s hard to explain what a feeling of confidence... we’re going to make it through this. All right, we’re going to get through this!

Mothers faced many other situations which were not a matter of life and death, although the decisions were hard to make nonetheless. The most challenging decisions juxtaposed the mothers’ personal wishes against what was in the best interest of her infant. They used terms like “selfish” to describe their desires and expressed feelings of guilt for even considering their own self-interests. When Emily contracted a cold while her twins were in the NICU she made the heartwrenching decision not to visit until the infection had cleared up. One day she made the hour-long drive to the hospital to deliver breast milk, but did not go in to see the babies:

Hardest thing I’ve ever had to do was leave that hospital that day. You know, I drove up here by myself and went in...and I walked out that front door all the way to my car just crying... And it was just the hardest thing... but I *knew* I was doing what was best for them. And as a parent I guess that’s what you have to learn.... That’s just what I had to keep in my mind, no matter what my thoughts and feelings are at this point, it really *is*

what's best for them, no matter how I feel about it necessarily... It's about somebody else and I guess maybe that's hope? Yes, but maybe just love.

Making decisions for your infant wasn't just hard for mothers, sometimes it was downright scary. They fretted over the potential consequences of their choice and felt the heavy burden of responsibility for their decision. Fran and her husband had a terrible time making the decision to have their now stable preemie transported back to a level II NICU closer to home:

It was probably one of the scariest things, after him being born that early, that probably happened the whole time because we had to make the decision if he was going to be moved.... And we're thinking what if we make the wrong decision? What if he gets in the ambulance and there's an accident? What if he gets in the ambulance and his temperature goes down too much and he gets hypothermia? What, I mean just all of the wrong things that were going to happen kept coming to our minds and then we ultimately had to make that decision.

Lack of Control/Powerlessness

Consistent in the experiences mothers related were feelings of powerlessness and a lack of control over what was happening to her and her infant. Several first became aware of hopeful feelings after watching their infants come through a distressing event—one which they could not change or control. Such was the case for Emily, whose son became apneic and turned blue in her lap, and Denise, whose son almost died from sepsis.

For most mothers the loss of control began with the onset of preterm labor or premature rupture of membranes and persisted for the duration of NICU hospitalization. Feelings about having no control ran the gamut from anger and frustration to loss, disappointment, and finally resignation. Not having the “natural” childbirth experience she had planned was a “huge loss” for Abby:

I was going to the birthing center and I was going have him naturally and then I was going to go home a few hours afterwards....after he was born

one of the greatest losses that I felt was that I would never have that feeling because of the C-section that I had with him, um you know, I'll never have a child natural. There's no chance of a V-back or anything and that's just a huge loss.

Beth mourned the loss of not finishing her pregnancy:

I just, was really disappointed because I was missing out on the rest of my pregnancy. I had just gotten to the point, and this was the selfish part of the thing, I had just gotten to the part where people like "Hey, you're pregnant!" And so I didn't get to have that, that special thing. I also didn't get to have the swollen ankles and, and being out to here... and feeling really done with it but, I don't know. I imagine, not having had any children before, that there's this like, like 8 months is great 'cause everyone, you're big and everybody's like "oh you're so beautiful and," and they put you on this pedestal because you're making kids. And I didn't get that.

After undergoing infertility treatments to conceive and placement of a cerclage to support a weak cervix, Emily endured 3 weeks hospitalized on bedrest for premature rupture of membranes and preterm labor before delivery became necessary for a footling breech presentation:

And I remember my doctor looking at me and saying "His foot is sticking out, we don't have a choice. Your babies are going to be born today." And I just lost it. I was just hysterical, you know, I *can't*! It's too early! And he just gave me the biggest hug and said "it's OK, they're going to be fine." And you know, they were so supportive on "you did all you could do, you did everything right, you've done the best job you could do, it's just time."

While antepartum bedrest was difficult to endure, she readily admitted she would have gladly laid there and watched TV and faced loneliness for another 3 months if it would have made things better for her twins later on. But of course, she was powerless to change what happened and was forced to accept the inevitable.

Often times mothers found they had no other choice than to simply accept that they could control very little of what happening, what problems their infant would develop, or how they would respond to such problems and treatment interventions. And it was in yielding themselves to the uncertainty of it all that some mothers were surprised to find their hopes and wishes had been fulfilled, or as Denise discovered, hope became knowledge:

All of a sudden it wasn't this wish, wishful thinking. Oh God please, please, please. When you pray for stuff like that it's *please* let this happen, *please!* If only you could do this. If only you could do. It's, it's a wish. It's an uncertainty.... I don't want to say hope because it's different, a different definition of hope...the desire for. Now it was knowledge. It's happening. We're getting it. You know it's not going to happen the way you want it to. It's not going to follow the...road that you wanted to follow, or go down the path that you wanted to go down, but it's happening. And you can watch it unfold. So it was no longer a plea, a begging plea. And there were times afterward, after we had got them home that I wish I had gone back to that. Because oh my god I got exactly what I asked for. Holy shit! Be careful what you ask for, you just might get it! And I did.

Feeling Like a Mother

For all its complexity and uncertainties, nothing stood out more in the mothers' experience of hope for herself than a deep, desperate desire to feel like she was a mother. No facet of the hope experience was more universal or more powerful than the longing mothers in the study felt to be a mother—*really* a mother. They longed to do the things that mothers normally do when they have a new baby and to feel all the good things new mothers are supposed to feel—the things preterm birth took from them. The one thing all the mothers did that facilitated this the best was pump their breasts and provide mothers' milk for their infant. Abby related: "I know for me it was really important. I pumped the whole time he was there and that was one thing that made me feel like a Mom— pumping milk." She reflected on how providing breast milk influenced her experience of hope:

It affected the feelings that I had.... I don't even know if it was hope for him so much as hope that I would feel like a mom. I mean he came out of me way before I was ready, way before he was ready. And we didn't even have a name, and it didn't feel like I was a mother you know. I had a scar and I had to heal and at night I had to take pain medicine and I had no child at home, you know-- nothing there. But there is a kid, I mean there is, you know. So it was more of feeling of me being a mom than hope for him. And maybe even more of a feeling like I hope one day I get to feel like a mom all the time.

Emily felt strongly about her milk contributing to growth and good health of her twins. Like other mothers in the study, she took comfort in knowing that it was the one thing she alone could do:

And even in the NICU that was something I could do for them. Can't do a whole lot...when I'm sitting in the hospital, you know, across the street and they're over there fighting for their lives. I can't do anything, but I can pump and bring it over there you know. So that was something I could do.

Being able to provide breast milk for her son helped Fran deal with the frustration of not being able to control things in the NICU:

My husband says I'm a control freak-- I like to do everything and I like to do everything my way. It was very, very weird for me for someone to say you can change his diaper *now* or you can take his temperature *now* or eventually you can hold him *now* instead of me just going and doing things. I remember when I was pumping my breast milk ...I had so much milk! I felt so great doing that for him because I felt like I can't hold my son when I want to, I can't do the things with him that I want to do, but I can get him the absolute best that I have that's going to make him better quicker. So that made me feel super. Made me feel like his Mom, where otherwise I mean I loved him and I was attached to him and I felt bonded to him but I didn't feel like his Mother because I couldn't do a whole lot

more for him.

Breastfeeding success was so important to Abby that she demanded that her son *never* be fed with a bottle. It was the one time she exercised her rights as a mother and attempted to control the acts of NICU professionals:

It went so far as I wouldn't let them give him a bottle, ever. The whole time he was in the nursery from the minute they started feeding him until he went home. Ever! ...because he latched on so well, and once he did that he was ready.... He sucked hard and I figured that if he could suck that hard at the breast there was no need to give him a bottle and I wouldn't let the nurses give him a bottle. Oh, they may have given him one when I wasn't there, but I didn't know about it.

Pumping and providing breast milk was the ultimate act of mothering—nourishing their babies—and with it they nourished hope for both mother and child. In an environment where nurse controlled almost everything, filling those jars with milk and stacking the freezer full became synonymous with being a good mother.

Mothers in the study had mixed emotions when it came to nurses in the NICU and maternal role fulfillment. Most felt some conflict over ownership of the child, conflict that could have been avoided by taking a less rigid stance towards caregiving in the NICU. Fran explained:

Everything was on such a schedule that they would say "Oh well it's 4 o'clock. You can," you know, "you can change his diaper" and whatever "now." But it was always when I was told, I never had the liberty to just go in and pick him up....It was frustrating.... I understood, I totally understood but at the same time it was just like, you know, when is it going to be, because I didn't feel like he was mine... Obviously I was bonded to him and everything else but I felt like he was the nurses' or the doctors' child more than he was mine.

Though mothers were very conscious of the "your baby, my baby" conflict, at the same time they were quick to praise nurses who "went the extra mile" or took time out of

their busy schedule to facilitate such normal mothering activities as bathing, or changing clothes. In this situation little things really did mean a lot. When I asked Emily what things made her aware of feeling hopeful, she responded:

Probably little things, like when I got to give them their first bath. That was probably the first time I really felt like hey, I *am* their mom and this *is* my child. You know, not that I didn't have that before because you know, I knew I was their mom and I knew they're my kids and everything. But it was really one of the first times I really did a "baby thing" with them. And when they got to wear clothes for the first time, I know that sounds silly but it was a big deal, that I got to bring their clothes for them. And they would put them in a bag when they got dirty, and I would take them home and wash them. And so I was doing something proactive for them as their Mom—that I would normally be doing. That's it, maybe that's what it is-- it's something *normal* that I was doing as opposed to, you know, having to scrub my hands and put on a gown before I held them or ask how many cc's they had been fed. That's not normal baby stuff. Bathing your children and washing their clothes was a *normal* baby thing. And maybe that's what it was, the fact that it was one of the first normal things I got to do for my kids. It's little, its minor kind of thing, but it was— I got pictures of it— It was a big moment. Yes, it was a Mom thing to do and that made a huge impact.

From the narratives of the mothers in the study it was quite clear to me that hope was an essential element in their experience of having a premature infant in the NICU. Hope became their anchor to hold on in the constantly changing world of the NICU. It was their "bridge over troubled waters" that provided the needed link from not knowing and uncertainty to knowledge and confidence in their role as a mother of premature infant. And when they felt alone and most vulnerable, mothers turned to hope and a Higher Power to pull them through:

I don't know how I did it. I can't really say... but I really think that God helps mothers...it's like something ingrained in you that's there, that you can pull from when you need it.... I don't think I could do it myself. I think it has to be a spiritual relationship that helps you get through. And I'm not a big church-goer, I don't know Bible verses....but I do know God and I'm a Christian and I think that really helped me get through it.

And finally:

We are truly blessed and I know that in our life there's a Higher Power watching— watching out over us and our kids. And we know that's what we were meant to be, and for whatever reason I was supposed to go through that with them. To help somebody else? To be able to support someone else? My life is forever changed because of my infertility, because of my high-risk pregnancy, because of having preemies I'm not the same person I was five years ago. I'm just not. And in a good way I think, a very good way.

Summary

Hermeneutic analysis of the transcripts from the six mothers who participated in this study revealed a consistency of themes comprising the lived experience of hope. The contextual ground was the World of the NICU—a world in which uncertainty, powerlessness, and the marking of time from admission until discharge were set against the backdrop of an unfamiliar environment perceived as negative by mothers. Included in this environment were others, namely neonatal professionals, who likewise were unfamiliar to mothers. It was within this context that mothers established a relationship with their infant, and it was within the mother-infant relationship that hope emerged. Elements of the ground became figural when they influenced hope as it existed within the mother-infant dyad.

Against the ground of the World of the NICU three prominent themes emerged: 1) hope and the infant, 2) hope and others, and 3) hope and the mother or self. Mothers took

their cues to have hope directly from their infant(s). Discouraging or encouraging events dictated the extent to which mothers felt hopeful. Others were figural in that they had a powerful influence on the hope that existed within the mother-infant dyad. This power either supported or threatened mothers' fragile hope. In the third theme the mothers addressed the conflict which existed in the juxtaposition of hope for my baby and hope for myself.

Within the theme of hope and the mother there were three sub-themes: 1) lack of knowledge/uncertainty, 2) lack of control/powerlessness, and 3) feeling like a mother. The first sub-theme reflected the mothers' need for concrete information upon which to build their hopes. In the face of uncertainty, mothers looked to the infant for cues such as color, vigorous behavior, or weight gain to communicate that the desired outcome—taking her infant home—was attainable. They also sought knowledge from neonatal professionals and outside sources such as books and the internet to counteract discouragement and build upon hopeful feelings. Feelings of powerlessness and the frustration mothers felt over having so little control in the NICU comprised the second sub-theme. In an environment where almost everything was controlled by others, participants were empowered in the mothering act of providing breast milk—the one thing they alone could do for their infant. Lastly, the desire to feel like a mother featured prominently in the mothers' need to feel hope for herself. Dejected by limited interactions with their infants, mothers found hope in each “normal” mothering act, such as holding, bathing, or breastfeeding.

CHAPTER FIVE

DISCUSSION

The purpose of this study was to describe the lived experience of hope for mothers of premature infants in the NICU. Using the existential-phenomenological approach developed by Pollio and Thomas (Pollio et al., 1997; Thomas & Pollio, 2002), I interviewed six mothers whose infants had been in the NICU for some period of time during the past 3 years about their experiences of hope while their infants were in the NICU. Following the hermeneutic process outlined in Thomas and Pollio (2002) study transcripts were analyzed by the researcher and in the interpretive group. A thematic structure of mothers' hope was elicited and the meaning of hope for these mothers illuminated.

Analysis of Findings

The language of hope and its diverse interpretations make hope an inherently complex and sometimes rather difficult concept to comprehend. In the English language, hope can be a noun, (hope), gerund (hoping), verb (hopes), or adjective (hopeful) (Farran et al., 1995). Perhaps hope is most commonly used as a verb, expressed as *I hope* or *she hopes*. In this form hope has no specific object and power to achieve hope belongs to others. Hope as a noun communicates a desired outcome or that which is possible, such as *there is hope for*. The object of the noun hope is revealed when expressed in the adjective form *hopeful*. Hope takes action in the gerund *hoping*, which then takes direction as either *hoping for* or *hoping against* its target. Hope, when used as a noun, implies a sense of achievement—something one has already conquered or has possession of, whereas the gerund hoping communicates a process— an endeavor to obtain the desired outcome¹

In the mothers' experiences in the NICU, hope was predominantly was a *hoping for* some desired outcome or event; or, in the language of phenomenology, their hope was

¹See discussion on *love* and *loving* in Pollio (1982, p. 11).

intentional. Not only was there intentionality in their hope, but mothers were very conscious of the direction of this hoping. Most of the time an awareness of hope emerged once mothers felt certain they knew what they wanted the desired outcome to be. When there was ambivalence, however, mothers spoke of not having hope or not knowing what to hope for—what direction their hope should take.

From the mothers' narratives of being in the NICU it was evident that hoping required significant effort on their part. They spoke of having hope as being hard, especially during those moments when uncertainty was particularly great or when improvement or making progress toward discharge was difficult to quantify. It was as though mothers' hope took an undulating path that seemed to parallel the "roller coaster ride" they spoke of as their journey through the NICU—hopeful feelings alternated with despair as they interpreted infants' cues as encouraging or discouraging.

The pain associated with having a premature infant was likewise implicit in their descriptions of hope as difficult or hard. For a brief moment mothers turned away from their infants to reflect on their own hopes at this time. Pain was expressed in feelings of guilt over the failure to carry their infant(s) to term. They used phrases such as "feeling like I didn't get to finish" and "coming out of me before he was ready—before I was ready" to describe how they failed their infants. The loss of carefully planned "natural" childbirth experiences were exquisitely painful for several of the mothers in this study. One mother cried as she spoke of her plans to deliver at a birthing center attended to by a midwife and a doula—a delivery she can never have in the future due to the emergency C-section required to save the life of her prematurely born son. Although these mothers were grateful to have doulas present during labor and delivery, anguish over having a high-risk delivery prevailed.

The mothering role presented as another avenue of pain for mothers in this study. With the care of the infant being controlled primarily by the nurses, perceived conflict over ownership of the infant was expressed in statements such as "I had no baby" and "I didn't feel like a mother." Attempts to counteract feelings of powerlessness through pumping and providing breast milk were helpful, but could not overcome the emptiness

and frustration mothers felt over their limited opportunities to freely “mother” their infant.

The Meaning of Hope

The meaning of hope for mothers of premature infants was revealed in the experiences shared by study participants. For these mothers hope had three foci: 1) life and death, 2) making progress or improving, and 3) being OK. Each focus was grounded in time, with life and death being of immediate or very short-term concern; making progress was an ongoing, yet short-term goal; and being OK addressed their long-term outlook for the future. In each aspect the mother’s primary focus was her infant; her own hopes, although important, were of much less concern to the mothers in this study.

Infant Cues

Mothers took their cue to have hope directly from their infant(s). Hope existed within the mother/infant dyad and all other influences on mothers’ hope were external to this relationship. An awareness of hope first emerged from within the context of the mother/infant relationship and was founded upon specific cues or behaviors mothers witnessed in their infant(s). Most of the time signals from the infant addressed the more immediate concerns of life and death or making progress. Principal cues spoken of by the mothers in this study included changes in color (blue vs. pink) and changing needs for respiratory support (high-frequency ventilator, conventional ventilator, CPAP, oxygen); however, they also watched for signs of improvement in increased feedings, decreased apneic episodes, and weight gain. Mothers assigned character attributions to their infants based on observed behaviors which suggested strength and an ability to overcome temporary set-backs in progress. Infant survival in the face of seemingly insurmountable odds, such as coming through surgery or recovering from near fatal infections and respiratory failure, were interpreted by mothers as a powerful communication of their infant’s will to live and “fighting spirit.”

Benchmarking

Once mothers had looked to their infants for cues upon which to base hopeful feelings, they turned outward to learn how to interpret the behaviors they had witnessed.. When facing the crisis of life and death, time was exceedingly short, thus mothers were wholly dependent on NICU professionals for information which would offer a sense of direction to their hoping. In less urgent moments mothers carefully gathered information from various sources. This knowledge became a benchmark upon which they could compare their infant's current condition and determine for themselves whether or not s/he was making progress toward the target of their hoping such as discharge.

Benchmarks are a way to structure time in the absence of precise markings and are used as a way to deal with uncertainty in situations where no clear, formal demarcations exist. They signify progress towards a goal or desired outcome and break time down into units which are more manageable (Pollio, 1982). In an environment where there are few formal divisions and time can seem endless, mothers use the information gleaned from talking with neonatal professionals, books about prematurity, the internet, and "graduate parents" who have experienced having a premature infant in the NICU previously to establish their own set of expectations for their infant. These self-imposed norms enabled mothers to better evaluate progress and minimized feeling like they would never get to take their infants home.

In addition to the norms mothers had formulated, they tried to assess how their infants were doing by making comparisons with other infants in the NICU. They often used terms such as *better* or *worse than* when making these comparisons. This process was limited, however, by perceived constraints on parent-to-parent communication mothers felt in light of the Privacy Rules set forth in The Health Insurance Portability and Accountability Act of 1996 (HIPAA) (U.S. Department of Health and Human Services [HHS], 2003). Reluctant to invade the privacy of another or break nursery rules, mothers made these comparisons in passing observations of infants adjacent to their own, such as when the infant came off the ventilator, was bottle fed, or transitioned from an incubator to a crib. Comparing the progress of their infant with that of others in the NICU served to

reassure most of the mothers in this study that their infant was making progress in achieving the developmental tasks of prematurity. One mother, however, had her sights set almost exclusively on going home with her son, thus each day she watched other infants leave it only added to her mounting frustrations.

The meaning of hope in *being OK* was not as clear-cut as the short-term concerns of life and death or making progress. Mothers spoke of hoping their child would be OK, but often did not specify what OK meant. One mother did qualify this hope by expressing the desire that if her son were to live, she wanted him to have a “quality of life”; nevertheless, this is still rather ambiguous. Mothers were more articulate about being OK when speaking of their own hopes. For them hoping was about acknowledging their failure to carry their infant to term and coming to accept the guilt they felt. Similarly, it was about going on in spite of failing their infant and working to be the best mother they could possibly be. Good mothering encompassed many things, including making decisions that were best for the infant even though they were not what the mother wished for herself. It was also about learning everything she could about prematurity and about her infant. Good mothering was about being there for her son or daughter and was demonstrated primarily through almost daily visits in the NICU. But most of all, good mothering was about pumping and providing breast milk to nourish her infant. Mothers spoke with pride about what good milk producers they were and about how many jars of milk they had accumulated in the refrigerator at the hospital and the freezer at home. They were explicit in associating the milk they were producing with hopeful feelings about their infants—their infants were going to be OK because of the good milk they worked so hard to produce.

Highlights in Study Findings

A final review of study data yielded several findings which were particularly noteworthy. The first had to do with the timing of mothers' hope. Mothers in this study were not aware of hope until after significant amount of time had elapsed since admission to the NICU, usually 2-3 weeks. There was a clear distinction between feelings of

optimism, which were present prior to birth and persisted throughout NICU hospitalization, and hope, which took time to develop. This was an unexpected finding, but was consistent across study participants.

Another surprising finding addressed the influence of family and friends on mothers' hope. All of the participants were married, yet only a few mentioned their husbands when talking about the NICU experience. When husbands were mentioned, it was in the context of how they responded differently to having a premature infant. One mother spoke of this difference as making "a stressful time a little more stressful," justifying his behavior as a means of protecting himself by not getting too close to the infant. Another mother spoke of the animosity her husband felt towards some of the nurses in the NICU, a feeling she shared to a lesser extent. It was unclear from the narratives as to the specific effects husbands had on hope, but limited mention of them suggests that husbands were not especially salient to the mothers' experience. Family and friends were likewise given brief mention in the experiences shared by study participants. A few spoke of their mothers or parents as being present and supportive, but there was little detail as to how significant others affected hope.

Likewise unexpected, another finding of this study highlighted the limited opportunity mothers had to find support and hope through parent-to-parent interactions. Study participants indicated there were no parent support groups offered by the NICUs. Several mothers felt constrained by the current emphasis on privacy related to the HIPAA regulations (HHS, 2003) to initiate communications with other families, thus missing out on a valuable source of support known to be beneficial to mothers in the NICU (Boukydis & Moses, 1995; Bracht, Ardal, Bot, & Cheng, 1998; Roman et al, 1995).

One mother in the study took an innovative approach to communicating with friends and family about her pregnancy and subsequent preterm birth and NICU experience by creating a website and blog about her son. In addition to the desirable effect of reduced phone calls from concerned family and friends, the daily progress reports offered the mother a mechanism for documenting each milestone achieved, and receiving an outpouring of love and support that boosted her morale and supported

hopeful feelings. Recent media reports document a growing trend towards the use of such websites and the beneficial effects gained from cyberspace communications (Alter, 2007).

Mothers spoke with clarity about the lack of control they had during the time their infants were in the NICU. From my previous experience and review of the literature this finding was not unexpected. What was unanticipated, however, was the utter lack of freedom mothers felt when it came to interacting with their infant independent of nursery personnel. The mother of a child who had a relatively smooth course in the NICU and spent most of his time as a stable “feeder-grower” went so far as to say that she was never at liberty to just go in and pick her son up. Every interaction between mother and baby had to comply with the nurses’ schedule and could be initiated only upon the direction of the nurse. Sadly, this situation was also consistent across study participants and highlighted the lack of progress made towards the actualization of family-centered care in the NICU.

Getting to hold their infants played a significant role in hopeful feelings expressed by most of the mothers in this study. They were greatly discouraged when they were not permitted to hold their infants and often holding was delayed until after ventilator support was no longer required. The frequency and length of time mothers were allowed to hold their infants were tightly controlled by the nurse—another source of frustration for mothers and an act which limited hope for these mothers. Even more stunning to this researcher was the absence of any mention of Kangaroo Care (KC) or skin-to-skin holding by mothers in this study. I find it difficult to imagine that, given the opportunity to engage in KC, mothers would not have mentioned it as salient to their experience of hope.

Assumptions

Several *a priori* assumptions provided the backdrop for this study of hope. These included: 1) hope is inherent in mothers of premature infants, 2) neonatal nurses affect mothers’ hope, 3) the NICU environment is detrimental to hope, and 4) personal religiosity affects hope. Secondary assumptions included: 1) mothers want direct, honest

information from neonatal professionals and 2) mothers want greater freedom and flexibility to engage in mothering acts with their infants. These assumptions were addressed by mothers in the study.

My first assumption, hope is something all mothers have or is inherent in mothers of premature infants, was not supported. Mothers in the study spoke of having positive feelings or an overall sense of optimism throughout their time in the NICU, but it wasn't until some critical event happened, usually witnessed first-hand, that a specific awareness of hope emerged. Once present, hope persisted for the duration of NICU hospitalization. Neonatal nurses affect mother's hope, my second assumption, was supported in the narratives shared by mothers in this study. Not only did nurses affect hope, they also played a significant role in the experience of hope. Nurses led the way in supporting hope most of the time. But the hope that most nurses carefully nurtured could be crushed in a moment by the words or actions of an insensitive or thoughtless nurse. Mothers seemed to be less forgiving of nurses dashing hope than of physicians.

The disquieting nature of the NICU environment to mothers is well-known, so it seemed logical to assume that it would have a negative effect on mothers' hope in this study. I was not at all surprised to find this assumption supported in the stories mothers shared about their time in the NICU. In one hospital the unit was undergoing a large remodeling project in which single-rooms were being incorporated into the design. Several mothers voiced optimism that the "new unit" would improve the hope experienced by mothers in the future.

My final assumption had to do with the personal religious beliefs of the mother and how actively she engaged in religious activities such as attending church or synagogue or reading religious materials such as the Bible. This assumption was not supported by the findings of this study. Few mothers attended religious services on a consistent basis and religion played no role whatsoever for some in the study. While selected mothers made reference to prayer, spiritual feelings, or a belief in God or a Higher Power, it was clear that hope was figural to all mothers regardless of religiosity. Given the limited number of participants in this study, however, it would be

presumptuous to arrive at any conclusion about the influence of religiosity on mothers' hope.

My secondary assumptions addressing the way in which neonatal professionals communicate with mothers and the freedom we allow mothers to have in the NICU were strongly supported by mothers in this study. Mothers depended on nurses and physicians to inform and educate them on what was happening with their children. They expected all information, be it good or bad, difficult to hear or joyous news, to be delivered in a kind, sensitive manner. They trusted professionals to be honest with them. Nurses were expected to be prompt, forthcoming, and liberal in sharing information about the infant. Mothers wanted to know everything about their infant and they didn't feel they should have to constantly ask to be told what was going on. Mothers also had a very hard time with nurses controlling every interaction and encounter they had with their infant. Not being "allowed" to do things or having to ask permission to touch or hold the baby or to even engage in such tasks as changing diapers or giving baths was an onerous burden for mothers to endure, especially as the infant neared discharge.

Significance of Findings

The findings of this study yielded an initial description of the lived experience of hope for mothers in the NICU and illuminated the meaning of hope for this population. Simply put, the study provided affirmation that mothers of premature infants have hope—hope that is vitally important to their ability to withstand the vicissitudes of life in the NICU. In the absence of previous research on hope in the NICU, the evidence found in this study offers a starting point upon which to build a body of knowledge of hope within perinatal-neonatal nursing. Moreover, this study builds upon extant knowledge of hope, thus advancing the state of the nursing science on hope.

Hope in Mothers of Premature Infants

When this inquiry into hope in the NICU was initiated there was only one study in the literature on the topic (Sherman et al., 1995) and it had significant difficulties. A few references to hope were found in the neonatal literature, most expressing parental

feelings for their prematurely-born child. Given the state of nursing science at that time, it was anticipated that this study would make a significant contribution to what is known about hope. An updated review of the literature revealed a few more references attesting to the importance of hope for NICU families (Charchuk & Simpson, 2003; Charchuk & Simpson, 2005), but no new research specifically addressing hope was uncovered.

Uncertainty featured prominently in this study of mothers' hope—a finding well-supported in the literature. Golish and Powell (2003) found uncertainty featured prominently in the griefwork of parents who had given birth prematurely. Mothers asked about their recollections of being in the NICU three years after discharge also reported vivid memories of the uncertainty they experienced during this time (Wereszczak, Miles, & Holditch-Davis, 1997). Working amid the uncertainty emerged as figural in a phenomenologic study of “maternal work” in NICU (Lasby et al., 1994). Stress, anxiety, and uncertainty were variables explored in the development of the Parental Stress Scale: NICU, an instrument that has seen extensive use in research with parents of premature infants (Miles, Funk & Kasper, 1992; Miles, Funk, & Carlson, 1993). To date there are no published phenomenologic studies specifically examining mothers' experiences of uncertainty in the NICU.

As anticipated, the experience of hope for mothers of premature infants was a complex, multifaceted phenomenon. The findings of this study highlighted those aspects of being in the NICU that had the greatest impact and offered insight into the areas of greatest importance to mothers. Mothers' hope emerged in interactions with their infants and interpreting the infants' cues. This suggests the need for greater nursing emphasis on helping mothers become more knowledgeable about the cues her infant is sending and in helping the mother to interact with her child based on such cues in a developmentally supportive manner. Extant literature on the techniques of providing developmentally supportive care is voluminous and offers strong evidence to support cued-based caregiving for mothers (Hawthorne, 2005; Lawhon, 2002).

The findings of this study are congruent with extant nursing literature on the detrimental effects of the NICU environment on mothers and infants. Key issues with

noise, lighting, equipment, and inadequate space and privacy addressed by mothers in this study are well-documented in the literature (Bruns & Klein, 2005; Byers, Waugh, & Lowman, 2006; Floyd, 2005; Gibbons, Geller, & Glatz, 1998; Glass et al, 1985; Krueger, Wall, Parker, & Nealis, 2005). Nursing research has looked at the effects of environmental stress on mothers in the NICU (Brunssen & Miles, 1996). Interventions to improve the environment in the absence of major structural changes were met with great resistance as nurses and physicians have been very reluctant to change attitudes and behaviors which would create a quieter, gentler environment.

At present a heated dialogue continues over the risk vs. benefit and cost of such things as incubator covers and sophisticated positioning aids which promote a more nurturing environment. Nevertheless, evidence of the deleterious effects of the NICU environment on long-term outcomes is mounting and hospitals are engaging in major remodeling projects to create nurseries which permit reduced ambient lighting, alternatives to audible alarms, remote monitoring, and increased space with more privacy for fragile preemies and their families. Mothers in the study spoke with optimism about one such remodeling project underway at a local hospital. They felt the new unit, which would offer private rooms for infants and families, would greatly improve the mothers' experience and better support hope.

In this study mothers' hope depended greatly on excellent communication with neonatal professionals. Nurses and physicians were the primary source for education about the problems faced by preterm infants, a finding supported in the literature (Brazy, Anderson, Becker, & Becker, 2001) Mothers expected to be told what was going on with their infant and what they could expect to happen in the coming hours, days, and weeks. The significance mothers placed on gathering information to help them deal with the uncertainties of the NICU supports the findings of previous research (Frank et al., 1997; Miles, Wilson, & Docherty, 1999)

Not surprisingly, feelings of powerlessness and the inability to control what was happening emerged as figural in the experience of hope in the NICU. From the earliest research with mothers of premature infants, powerlessness has played a prominent role.

While some aspects of powerlessness are inevitable in preterm birth, much can be done to counteract the lack of control perceived by mothers. Establishing effective partnerships with mothers and implementing family-centered, or more recently, family-focused care can go a long way towards returning control to the mother where it ultimately belongs (Bruns & Klein, 2005; Bruns & McCollum, 2002; Dobbins et al., 1994; Gretebeck et al., 1998; Heerman et al., 2005; Krebs, 1998; McAllister & Dionne, 2006)

Closely related to the powerlessness felt by mothers in the study was the emptiness of having given birth but not feeling like a mother. Mothers struggled to find hope in the face of an empty uterus and empty arms, or as one mother put it: “I had a scar...and I had no child at home, you know—nothing there.” What mothers wanted most, second only to their child living, was to feel like a mother. Unfortunately NICU care is prioritized to meet the needs of the infant first and the nurse second, leaving mothers to fight for what they want and need, as Abby did in forbidding her infant to be bottle-fed, or acquiesce to the nurses and feel frustrated by the restrictions like Fran. There is enough research-based evidence (Bialoskurski, Cox, & Wiggins, 2002; Cescutti-Butler & Galvin, 2003; Fenwick, Barclay, & Schmied, 2001; Lupton & Fenwick, 2001; Wigert, Johansson, Berg, & Hellström, 2006) documenting this issue that it is no longer acceptable for nurses to dominate possession of the infant and deny mothers the freedom to do what is best for the mother-infant dyad; that is, let them mother!

It was the consensus of the mothers in the study that the one thing that best served to promote feelings of motherhood and nurture hope was their ability to provide breast milk for their infants. The literature is replete with articles extolling the virtues of breastfeeding for all newborns and preemies are no exception (Vohr et al., 2006). Having a child suckle at the breast and hooking oneself up to an electric breast pump, however, are drastically different experiences. Despite these differences, the mothers found great satisfaction in knowing they were giving the very best they had for their infant, something that no one else could do. Even time spent alone while pumping proved to be a time for meditation and reflection—a comforting constant in a sea of uncertainty.

Hope in Nursing Science

In reviewing the results of this study, I found that the description and thematic structure of the experience of hope for mothers of premature infants was congruent with prevailing definitions of hope found elsewhere in the nursing literature. In particular, the experience of hope for mothers in the study was compatible with the description of hope outlined by Dufault & Martocchio (1985):

Hope is a multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant.... Hoping is not a single act but a complex of many thoughts, feelings, and actions that change with time (p. 380).

The multidimensionality of hope for mothers of premature infants was evident in the three facets of the hope pyramid— infant, self, and others; its inverted position symbolic of the dynamic nature of hope given the relentless uncertainty that exists in the world of the NICU. In the face of uncertainty, mothers were generally optimistic about their infants. Even when precariously perched upon the precipice of life and death, mothers in the study were never hopeless—that glimmer of hope remained however dim the situation appeared to be. While riding the roller coaster that is parenting in the NICU, they held fast to hope until that day the roller coaster came to a screeching halt. Then they took hold of their precious preemie, walked out the door of the NICU for the last time and went home; having achieved their dream at last.

Dufault and Martocchio describe hope as generalized or particularized. Generalized hope is more broad in scope and addresses an overall sense that something good or beneficial will come, but without the specifics to support such a positive outlook. Generalized hope is viewed as protecting a person from despair and offering a sense of meaning to life. This type of hope was referred to as positive feelings by mothers in the study—a sense of optimism that presided over their entire NICU experience. This sense supported Abby and Denise when the evidence from their infants pointed to almost-certain death; in times of desperation they were never hopeless.

Particularized hope has an object or specific focus. It is hope for something or someone. In the NICU this hope was seen in all the little things their infant did: gaining weight, coming off the ventilator, weaning off oxygen, tolerating feedings, moving from the incubator to a crib. Every cue the baby offered nurtured hope. This hope was influenced by every encounter with a neonatal professional, be it supportive or destructive. Ultimately this hope was found in the maternal role. From each drop of precious breast milk produced to every soiled diaper changed, nothing had greater lasting impact on mothers in the study than doing the things that normal mothers do for their newborn infants every day.

Strengths

The study had many strengths which enhance its value within the body of nursing research. First of all was the chosen research method, the Pollio-Thomas approach to phenomenology. Knowledge of hope in mothers of premature infants is sparse, and choosing a qualitative methodology in which there are no directed questions and the participant is the acknowledged expert allowed the mothers to describe what hope was for them. The accrual of individual meanings enabled a description of hope to emerge from the data that was free from researcher bias as much as possible.

Another strength of the study was the diversity of infant maturity represented. From 23 week twins born at the very limits of viability to mid-range mature infants at 31 weeks, mothers in the study had preemies with a wide range of issues typical of infants admitted to the NICU. This diversity of gestational age was desirable in order to uncover a thematic structure of hope that is representational of the infants and families neonatal nurses care for on a daily basis.

The length of time elapsed from when the infants were born until the mothers were interviewed was another strength of the study. Ranging from 10 months to 2 ½ years, mothers had enough time to adjust to caring for their infants at home and to reflect on their time in the NICU without the time interval between hospitalization and the study being overly long, which could have called into question the mothers' ability to recall the

specifics of the NICU experience.

Finally, the diverse spiritual and religious backgrounds of the mothers added credence to the findings of this study. Perhaps if all the participants had similar religious affiliations or were actively engaged in what might be perceived of as extreme religious behaviors, the findings of the study might have been less representative of that which is most common in the NICU.

Limitations

Limitations of the study were primarily sample-related issues and reflected in part the difficulty I had in recruiting study participants. I only had 6 participants in this first study of mothers' hope. While I feel confident that 6 mothers were adequate to elicit a thematic structure of hope, additional interviews with mothers are needed to explicate what hope is for a larger group of mothers. Study participants lived within a relatively small geographic area and represented only 4 NICUs. There are definite differences that exist among nurseries located in different geographic areas; there are socio-cultural differences and philosophical differences in addition to basic structural differences among NICUs. This study could not capture the potential influence of these differences on hope.

There was also limited diversity among the mothers who participated in this study. They were all white, Euro-American women in monogamous married relationships who had college educations and would be considered to be middle-class Americans. The stories they shared with me were rich with emotion and clearly reflected the uniqueness of each mother. I can't help but question, however, if the lived experience of hope might look somewhat different for adolescent mothers, mothers who live in impoverished conditions, those who live in other places, and mothers from a diversity of cultures and races. Further research is needed to answer these questions.

Mothers of premature infants are not the only ones whose lives have been touched by having an infant in the NICU. There are mothers of infants born at term who become critically-ill and require intensive care. Extant literature suggests they have a different experience in the NICU. Additionally, there are infants in the NICU born with congenital

heart disease or other anomalies. Surely hope plays a role for those mothers as well, although it was not addressed in this study. Fathers, grandparents, and significant others are affected when an infant is admitted to the NICU. Future research on hope should also include these key players.

Finally, neonatal nurses and other NICU professionals have a crucial role in the care of critically-ill newborns and their families in addition to their technical expertise. Their attitudes and experiences of hope also need to be explored. If hope is a universal lived experience of health as Parse (1999a) proposed, then individual differences among NICU professionals need to be considered and their experiences of hope explored. With a better understanding of hope for both parents and professionals, current practices can be critically evaluated and changes proposed which will better nurture hope for everyone in the NICU.

Implications for Nursing

The findings of this study offer insight into the experience of hope for mothers of premature infants in the NICU. It was a privilege to have the opportunity to listen to these mothers share their stories—stories they eagerly shared with the fervent hope that the lessons learned from their experience would benefit mothers who unexpectedly find themselves in the NICU in the future. As such, the results of this study have implications for nursing education, practice, policy, and research in the future.

Education

Nurses develop basic skills for interacting with patients and families in their initial nursing education. It is important to address hope in our teaching, both in the classroom and at the bedside, and to instruct nurses in the techniques of sensitive communication and the development of empathic behaviors. Successful caring in nursing begins with a caring demeanor and considerate communications. It is also important that nurses be educated in the theory and practice of family-centered care (FCC), emphasizing the inseparable nature of mother and infant. Nurses committed to FCC recognize the mother as the most important person in the child's life and give priority to the care of

both mother and infant in the NICU. Given a strong foundation promoting FCC, nurses are better prepared to adopt these principles and put them into practice as perinatal-neonatal and pediatric nurses.

Practice

The findings of this study are replete with implications for neonatal nursing practice. First and foremost, the experiences shared served as a reminder to nurses of just how fragile mothers really are while their infant is in the NICU. They are exquisitely sensitive to our attitudes, words, and actions—one unkind encounter with a nurse can inflict devastating wounds on an already traumatized heart. Neonatal nurses need to remember to care for the mother with the same tenderness shown her infant. One way nurses can accomplish this task is to help the mother feel welcome in the NICU. Currently they feel more like outsiders who don't belong than the mothers of newborns who need the nurturing that they alone can provide. The perception of mothers as outsiders is perpetuated by decades of tradition in the NICU. In light of the evidence from this study and others in the literature, however, it's time that neonatal nurses renew their commitment to create an environment in which mothers know they are the *mother*—the one whose presence is critically important to the well-being of her infant(s). The recent trend towards structural remodeling of units constructed in the late 20th century and the implementation of single-room neonatal care offers an exciting step forward; but unless the attitudes and practices of neonatal professionals change, the emotional climate of the NICU will continue to send the message that families are visitors. As long as families remain visitors NICU professionals monopolize control of the infants, which control helps to ensure that mothers are less likely to know the joy and hope that comes from actively mothering their precious premature infant.

Perceptions of belonging and feeling comfortable in the NICU are perhaps best enhanced by the manner in which neonatal professionals communicate with mothers. Eliminating the word *visitor* from our vocabulary is a good way to initiate change in the balance of power. From the first time families enter the NICU they are put in the position of outsider by a sign indicating the times they are permitted to visit. Denying entrance to

the unit for rounds and shift changes further separates mother from infant and communicates their role as less important. Maybe it's time for nurses to start asking mothers what they would like us to do in order to help them feel more comfortable. A study participant suggested that nurses needed to be more directive in insisting parents participate in caregiving. Initiating this engagement by asking the mother how she would like the nurse to assist her in caring for her child seems completely appropriate, especially in those last few weeks before discharge.

While nurses' caring actions may not change, the way such care is phrased communicates to the mother that she has control and is capable of meeting her child's needs. The use of "we" language implies a shared responsibility to care for the infant and sends the message that parents and professionals are of equal importance in accomplishing this task. Becoming acquainted with the mother as a person and inquiring as to her specific needs, desires, preferences, and beliefs helps mothers feel like they belong in the NICU. Feeling comfortable in the environment frees mothers to focus on adapting to their maternal role which in turn, enhances hopeful feelings.

Neonatal professionals had a profound effect on the hope experienced by mothers in this study. One of the things mothers requested from physicians and nurses is that they be told the good news along with the bad news. One mother opined that she was told everything that could go wrong but no one told her what could go right with her infant. Nurses need to be sure mothers see what's going right, no matter how small that forward progress may be, in order to nurture hopeful feelings. Mothers often felt overwhelmed by the whole situation and needed nurses to help them focus their sights on the little signs of progress when all they could see was the big picture; on the other hand, they need help visualizing the big picture when all they could see were the little facts and figures they had come to depend on to measure progress.

Supportive communications with professionals facilitate feelings of hope for mothers in the NICU; however, unless that professional has had their own premature infant, they cannot fully appreciate what that experience is like for mothers. There are simply some things that mothers need to hear from other mothers about what the journey

of having a preemie in the NICU is like. Books about prematurity are helpful, but books read by the mothers in this study focused primarily on the infant. A recent mass market publication by Davis and Stein (2004) does an excellent job of addressing the emotional aspects of having a premature infant; nevertheless, mothers want opportunities to talk with other mothers who share this experience. It is important for nurses to foster these parent-to-parent communications, both among parents who currently have infants in the NICU and with “graduate parents” who have previous NICU experience. If a parent-to-parent support group is not currently available, nurses should attempt to compile a list of graduate parents who would be willing to speak with current parents as the need arises.

Several mothers in this study mentioned the negative impact HIPAA regulations had on their feelings of hope as nurses implicitly and explicitly discouraged parent-to-parent contact and communication in the NICU. The HIPAA Privacy Rule was put in place to assure privacy of personal health information in the transmission of data among health care providers, health plans, and business associates—especially data transmitted by electronic means (HHS, 2003). In no way does this regulation prohibit nurses from encouraging parents to talk to each other. While nurses are not at liberty to disclose specific information about other infants in the NICU, they certainly can speak in generalities about other infants and families when trying to assist a mother dealing with uncertainty and feelings of isolation in an overwhelming environment.

Opportunities and issues surrounding holding their infant were figural to all the participants in this study of hope. Simply put, they did not begin to feel like they were a mother until they had that first opportunity to hold their baby in their arms and look into his or her face the way mothers of healthy infants born at term do. From the classic research by Rubin (1961, 1967a, 1967b) it is well-known that holding and *en face* positioning between mother and infant are among the essential first steps to maternal role attainment. As neonatal nurses, we have an obligation to see to it that mothers hold their infants as soon as possible after birth. This first holding experience may not be a swaddled bundle and the mother may not be sitting in a rocking chair, but even slipping the mothers arms underneath the blankets and lifting her intubated son or daughter up

briefly while the nurse changes soiled blankets on the radiant warmer offers that first encounter that means so much to mothers' hope.

Policy

The findings of this study highlighted areas of concern in current health care policy. Especially salient to the mothers in this study were issues of privacy and perceived constraints on interactions among families in the NICU. The privacy rules set forth under the HIPAA act (HHS, 2003) were never intended to impose such restrictions on personal and community support systems such as those found in parent support groups or on the interpersonal communications among families of patients. It is important that those charged with implementing such policies communicate to health care professionals what is *not* required under the Privacy Rules as well as what is required. Failure to achieve balance in the implementation of policy places an onerous burden on patients and families—a burden that discourages families from seeking and obtaining the support they need during times of crisis.

The experiences shared by mothers in this study also highlighted the anguish that results when families are treated as visitors in health care settings. Moreover, this anguish is extended when unit and hospital policies restrict or exclude persons important to patients from being present and participating in the care and support of patients and families. It's time nurses embrace family as defined by the Institute for Family Centered Care (IFFC, 2007): "Two or more persons who are related in any way—biologically, legally, or emotionally." According the IFFC, parents define who their families are. If a person is important to the mother, then they should be encouraged to be present with the mother as she cares for her infant in the NICU. In light of mounting evidence documenting the damaging effects of restricted visiting practices, a significant shift in attitudes and policies which remove these barriers is long past due. In the NICU it is no longer acceptable to exclude friends and family members, especially siblings, from embracing the mother and infant at the bedside in the NICU. Such restrictions were a source of great frustration and discouragement to several study participants, yet they had no avenue to protest the exclusion of children. Nursery policies should establish

procedures to screen children for potentially concerning health problems, but healthy children should not be prohibited from entering the NICU simply because it's cold and flu season.

Research

The findings of this study support extant work concerning the concept of hope for nursing science and provide new insight to hope within neonatal-perinatal nursing. Additional research is needed to further explicate the lived experience of hope for mothers of premature infants. These studies will attempt to describe the experience of hope for adolescent mothers and those from a more diverse geographic and socio-cultural background. The impact of single room neonatal care offers new horizons for hope research. And finally, research with fathers and other family members as well as neonatal professionals, especially nurses, is also needed to fully understand the experience of hope in the NICU.

Conclusion

Having hope was important to the mothers participating in this study. Hope did not present itself immediately upon the birth of a premature infant and admission to the NICU, rather it took time for mothers to develop an awareness of hope. Hope did not emerge as figural until after the mother had time to recuperate from delivery and the complications of her pregnancy, then adjust to the overwhelming nature of the NICU environment. Mothers had to learn to deal with uncertainty, powerlessness, and the influence of others as they journeyed together with their infant from admission until discharge from the NICU. Along the way, mothers had to learn how to balance the hope they felt for their infant with their own need for hope as one step in the process of becoming a mother to a premature infant.

For the mothers in this study, having hope meant dealing with the immediate concern of will my infant live or die. Once confident that the infant would survive, mothers turned their attention to seeking cues from the infant which indicated s/he was making progress towards the goal of being well enough to go home. And finally, hope for

mothers meant that both they and their infant would be OK in the future, although mothers did not necessarily define what constituted being OK.

Nurses and other neonatal professionals had a significant role to play in the hope experienced by mothers in the study. Mothers were greatly affected by the attitudes and communications of nurses. Other family members and friends played somewhat lesser, but nevertheless important roles in supporting hope. Neonatal professionals have tremendous power to influence mothers' hope. By engaging in caring practices consistent with the principles of developmentally supportive, family-focused caregiving, neonatal nurses have the opportunity to nurture hope at a time when mothers are most vulnerable. Nurses can encourage mothers to feel comfortable in the NICU and help them in assuming their rightful role as the most important person the child's life—the mother.

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APPENDIX

CONSENT FORM

The Lived Experience of Hope in Mothers of Premature Infants in a Neonatal Intensive Care Unit

You are being asked to take part in a research study. The purpose of the study is to describe mothers' experiences of hope while their premature infants were in the Neonatal Intensive Care Unit (NICU). Participation is strictly voluntary. If you choose to participate, an experienced neonatal nurse will conduct an interview with you that will last about one hour (maximum 1½ hours) in a quiet, private place of your choice. You will be asked to share your experience of hope while your premature infant was in the NICU (aka Intensive Care Nursery). The interviewer will ask a question, then you will talk about the things you remember most about hope during the time your baby was in the NICU. The interviewer will ask more questions based on what you talk about during the interview. A cassette tape player will be used to record the interview. The audiotape will be transcribed into written text so that the researchers can use your exact words to study your experience. Your name will not be on the tape or written transcripts. The names of people or places you talk about will be changed on the written transcripts so no one can identify who you are, who helped take care of you, or what hospital your baby was in. The tapes and transcripts will be kept in a locked file at the University of Tennessee College of Nursing and no one except the researchers will have access to them. The audiotapes will be destroyed once the study is completed. A single copy of each transcript with identifying information removed will be kept in a locked file for further analysis.

Having a premature infant in the NICU is stressful. Talking to the interviewer about your experience may cause old feelings to return, some of which may be unpleasant or uncomfortable. The interviewer will be very respectful and sensitive to your feelings. If talking about your experience becomes too distressing, you may ask to stop at any time during the interview. By sharing your experience you will let nurses and other professionals know what the mother's experience of hope in the NICU is really like. This may inspire nurses to be more supportive of mothers who have premature infants in the NICU in the future. You may also benefit personally from having the opportunity to share your story with an interested, experienced neonatal nurse. You will receive no incentive or monetary compensation for participating in this study.

All information you give the researcher is confidential. Your name and other identifying information will not be shared with anyone except those conducting the research. Your exact words may be used in written reports and presentations of the completed study but no one will be able to link you to the words in the final reports. Reports of the study may be published in books or professional journals so others can learn from your experience.

You are free to choose to *not* participate in this study. You may withdraw at any time by contacting Kristina Plaas or her faculty advisor Sandra Thomas. Your audiotape and written transcript will be destroyed if you choose to withdraw from the study. There is no penalty of any kind for withdrawing from the study.

Participant's Initials: _____

If you have questions about the study or if you experience adverse effects as a result of participating in this study, please contact:

Kristina M. Plaas, MSN, RN, (865) 693-9496

Sandra P. Thomas, PhD, RN, (865) 974-7581

The University of Tennessee College of Nursing

1200 Volunteer Blvd.

Knoxville, TN 37996-4180

If you have questions about your rights as a participant in this study you may contact the University of Tennessee Office of Research Compliance Officer at (865) 974-3466.

I have read the above information. I have received a copy of this form. I agree to participate in this study.

Participant's Signature: _____ Date: _____

Investigator's Signature: _____ Date: _____

DEMOGRAPHIC DATA FORM

Age: _____

Race: _____

Education (check one):

_____ Less than high school

_____ High School graduate

_____ Some college

_____ College graduate

_____ Master's degree

_____ Doctoral degree

Occupation: _____

Marital Status (check one):

_____ Single, never married

_____ Married, never divorced

_____ Separated

_____ Divorced

_____ Widowed

_____ Remarried after divorce

_____ Remarried after widowed

How many times have you been pregnant: _____

How many children have you given birth to: _____

(continued on next page)

How many miscarriages have you had: _____ abortions: _____ stillbirths: _____

How many premature births have you had (born > 3 weeks *before* your due date): _____

How premature was this baby: _____ weeks of gestation *or* _____ weeks early

How many babies did you have with this pregnancy (check one):

_____ One

_____ Two

_____ Three

_____ Four or more

Problems during pregnancy (check all that apply):

_____ High blood pressure/toxemia

_____ High blood sugar/gestational diabetes

_____ Infection, please describe: _____

_____ Premature labor

_____ Bleeding, please describe: _____

_____ Other problems, please

describe: _____

Treatments your baby received (check all that apply):

_____ Oxygen

_____ Ventilator or CPAP

_____ IV fluids or medication

_____ Tube feedings

_____ Surgery, please describe: _____

(continued on next page)

_____ Other treatments, please

describe: _____

How long was your baby in the NICU? _____ weeks

Religious preference (check one):

_____ Catholic

_____ Jewish

_____ Muslim

_____ Protestant

_____ Latter-Day Saint

_____ Other, please specify: _____

How often do you attend religious services? (check one)

_____ Almost every day

_____ 1-2 times a week

_____ 1-2 times a month

_____ 6-11 times a year

_____ 1-5 times a year

_____ Less than once a year

_____ Never

Thank You!

CONFIDENTIALITY PLEDGE OF RESEARCH GROUP MEMBER

I, _____, pledge to maintain confidentiality of all interview data discussed in the phenomenology research group led by Dr. Howard Pollio and Dr. Sandra Thomas at the University of Tennessee, Knoxville. Even though no names of participants or places appear on the typed transcripts, nor are any identifiers revealed during the group discussions, distinctive portions of dialogue or details of events could still be identifiable in some cases. This means I will not reveal any words, phrases, or possible identifiers of research participants in any conversations within or outside the university at any time.

Date: _____

VITA

Kristina Maria Plaas was born on 6 June 1959 to Dr. Hyrum and Johanna Westerduin Plaas in Salt Lake City, Utah. She graduated with honors from Farragut High School in Knoxville, Tennessee and pursued nursing studies at The University of Tennessee, Knoxville College of Nursing, receiving her B.S.N. degree with honors in 1981. She continued her education to become a perinatal-neonatal clinical specialist, graduating with a M.S.N. degree from Vanderbilt University in 1990. She later returned to The University of Tennessee, Knoxville and received a Ph.D. in Nursing in May, 2007.

Kristina has more than 20 years experience in neonatal nursing, having worked in NICUs in Tennessee and Utah. She was the recipient of the Robyn Main Excellence in Clinical Practice Award presented by the National Association of Neonatal Nurses in 1990. She was named to Marquis' Who's Who in American Nursing, Who's Who in the West, Who's Who of American Women, Who's Who in Medicine and Healthcare, Who's Who in America, and Who's Who in the World. She has served in leadership capacities with the National Association of Neonatal Nurses and the Utah Perinatal Association and is member of Sigma Theta Tau International Honor Society of Nursing and the Southern Nursing Research Society. The author of numerous clinical practice guidelines and standards, she has established procedures for the evaluation of products and equipment used in the hospital setting and has served as a consultant to major medical device manufacturers in the development of products and equipment for neonatal patients.