

UNIVERSITY OF MIAMI

**NAVIGATING THROUGH UNCERTAINTY:
BREASTFEEDING THE HIGH-RISK INFANT**

By

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A DISSERTATION

**Submitted to the Faculty
of the University of Miami
in partial fulfillment of the requirements for
the degree of Doctor of Philosophy**

Coral Gables, Florida

May 2000

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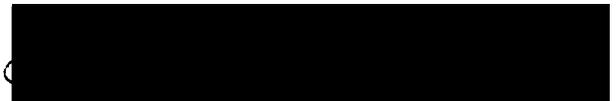
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Navigating Through Uncertainty: Breastfeeding the High-risk Infant

(May 2000)

Abstract of a doctoral dissertation at the University of Miami.

Dissertation supervised by Dr. Nancy Hogan

No. of pages in text. (89)

The purpose of this study was to understand the breastfeeding process mothers' face with their high-risk infants. Grounded theory methodology was used in this qualitative study to capture the richness of this experience. A purposive sample of 20 breastfeeding mothers, with diverse cultural backgrounds, whose babies had been discharged from the neonatal intensive care unit, was recruited. Open-ended, interactive, telephone interviews were conducted to obtain data. Coding procedures and constant comparative analysis were utilized for the simultaneous data collection and analysis. The core category that emerged from the data was, "Navigating through Uncertainty". Mothers described breastfeeding the high-risk infant as a "process that happened slowly over time" and was "full of unknowns". Five major categories observed in the data and subsumed by the core category included, Realizing something is wrong, Enduring the "heartbreak", Living with the changing reality day-by-day, Being a mother in the NICU, and Mothering the baby at home. The findings of this study suggest that these mothers exhibit physical and emotional stamina in their pursuit to breastfeed. Implications for nursing practice include providing parents with increased support systems and resources while the infants are in the NICU, helping mothers develop realistic expectations concerning the progression of breastfeeding, and offering anticipatory guidance and follow up resources for mothers as their infant approaches discharge.

Dedication

**To all the mothers and babies who have, and those who will,
live through this experience...
and
To all the nurses who touch their lives
in caring moments...**

Acknowledgements

**I gratefully acknowledge my chairperson, Dr. Hogan, and my committee members,
Dr. Gesse, Dr. Labadie, Dr. Ugarriza, and Dr. Berry.
The support, guidance, and inspiration they have provided me with is greatly appreciated.**

**A love filled thank you to my sweet children,
Alexis, Frankie, and Henry.
They have taught me that breastfeeding is much more than feeding a baby at the breast.
It is a life lesson of love and interaction that lasts long after the weaning.**

**I extend a profound thank you to my dear friend,
Kandy,
her unremitting support, encouragement, and humor has kept me moving onward
through tumultuous times.**

**Lastly, I lovingly acknowledge my parents,
Helena and Henry,
for their never ending nurturing,
which has made it possible for me to grow in this way.**

I thank you all from the bottom of my heart.

--Susi--

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CHAPTER I

Introduction

Background and Significance of the Problem

There is a plethora of evidence to support the benefits of breastfeeding for mothers and their infants. Breastfeeding improves the health of babies. "It is disease prevention in its purest form" (Riordan, 1997). As early as 1892, medical literature provided data that milk from numerous species, including humans, was protective for the offspring because of its antibody content (Mathur, Dwarkadas, Sharma, Saha, & Jain, 1990). Some of the components of human milk that have protective properties are: macrophages, polymorphonuclear leukocytes, lymphocytes, immunoglobulins, bifidus factor, resistance factor, lysozymes, lactoferrin, interferon, complement (C3, C4), B-12 binding protein, gangliosides, and interleukin (Lawrence, 1994).

Researchers suggest that human milk is effective in controlling and even preventing infections in the infants who receive it. Several researchers have documented the protective effects of breastmilk against respiratory infections (Holberg, Wright, Martinez, Ray, Taussig, & Lebowitz, 1991; Lopez-Alarcon, Villalpando & Fajardo, 1997). Breastfed babies also have fewer gastrointestinal infections (Dewey, Heinig & Nommsen-Rivers, 1995; Howie, Forsyth, Ogston, Clark, & Florey, 1990). Researchers have documented a decrease in occurrence of otitis media in breastfed babies (Duncan, Buchanan, & Renwick, 1993). Studies also show a protective effect of breastmilk against allergies (Cunningham, Jelliffe, & Jelliffe, 1991; Saarinen & Kajosaari, 1995). Researchers have even documented that babies who receive breastmilk score higher on

mental development tests and may actually have higher intelligence quotients (Lucas, Morley, Cole, Lister & Leeson-Payne, 1992).

Not only does breastfeeding offer these benefits, but it contains the perfect nutritional composition for infants. Human milk is rich in proteins, lipids, oligosaccharides, vitamins, and minerals. Breastmilk also contains hormones, enzymes, and growth factors. Approximately 10% of breastmilk is composed of solids for growth and energy and approximately 90% is water (Riordan & Auerbach, 1993). Human milk is species-specific and is therefore, the perfect, most appropriate food for human babies.

Breastfeeding also benefits mothers. Mothers who breastfeed experience a quicker return of the uterus to its prepregnant state and more rapid weight loss in the first months postpartum (Lawrence, 1994). Breastfeeding also offers a reduced risk to the mother for developing osteoporosis and breast cancer (Lawrence, 1994). Providing milk for one's infant facilitates the interactive attachment process between mother and infant (Bowlby, 1951; Harlow & Harlow, 1965; Klaus & Kennell, 1975; Rubin, 1967). Bonding with the infant in this way supports attainment of the maternal role (Rubin, 1967).

Protecting, promoting, and supporting breastfeeding has become an international responsibility. Awareness of this obligation is apparent in the joint efforts of the World Health Organization (WHO) and UNICEF in their creation of the "ten steps to successful breastfeeding" (1989). These steps are to be implemented in every facility providing maternity services and care of newborns worldwide.

National goals for breastfeeding have also been explicated in the "Healthy People 2000" document. The United States Public Health Service (1978, 1990) defined national goals to be achieved by the year 2000 (1978, 1990). These goals included the following:

an increase to at least 75 % of mothers who breastfeed at hospital discharge and an increase to at least 50 % of mothers who continue to breastfeed at six months (Healthy People 2000; 1990). The reporters further state that special populations where breastfeeding rates are particularly low, should be targeted because breastfeeding is the optimal way of nurturing infants while simultaneously benefiting the lactating mother. The most recent Healthy People document (2010) provides statistics indicating that the goals set for 2000 were not achieved. The 1998 baseline statistic for percentage of mothers breastfeeding in the early postpartum period was 64%. This statistic fell short of the target set for 2000, which was 75%. Therefore, the 2010 target will remain at 75%. The 1998 baseline statistic for percentage of mothers breastfeeding at six months was 29%. This too fell short of the target set for 2000, which was 50%. Therefore, the target for 2010 will remain at 50%. Related to the American Academy of Pediatrics most recent position statement (1998) concerning breastfeeding promotion for the first year of life, a goal has been set for 25% of mothers to be breastfeeding at one year. This goal is to be achieved by 2010. The 1998 baseline statistic reveals only 16% of mothers breastfeeding at one year. Specialized populations, such as breastfeeding in the high-risk infant, have even lower incidence of breastfeeding.

High-risk infants are those who are born requiring intensive care. Diagnoses of infants admitted to the neonatal intensive care unit include, but are not limited to: prematurity, respiratory distress syndrome, sepsis, hyperbilirubinemia, or congenital abnormality. These infants are born with a compromised health status. At the time of birth they are weak, stressed, and unstable. For some the instability can last days, weeks, and even months. Survival of these infants is the greatest concern. Neonatal death is a

somber potential outcome. These infants require intensive, continual, assessment and monitoring. Interventions to support the viability of these infants are extensive and highly specialized. The environment in which these infants are cared for is detailed and comprehensive. At times the NICU can appear calm, quiet, dimly lit and subdued. However, this can change in an instant. There always lurks the potential for a major medical emergency. The atmosphere in the NICU can change from moment-to-moment and the parents who visit their infants can sense this underlying tension and flux.

The nature of the NICU environment creates obstacles to breastfeeding. These intensive care units are not relaxed and cozy, they are technical and busy. Nurses and doctors are focused on keeping the infants alive. The unit is open so that all babies are accessible, this however, can decrease privacy for parents visiting their infants. There are insurmountable odds challenging the mother who wants to breastfeed her infant in the NICU environment.

In spite of the critical nature related to the care of these high-risk infants it is important not to lose sight of the tremendous benefits of providing breastmilk to this population of vulnerable infants. The health benefits of providing breastmilk to high-risk infants are being studied with great vigor. High-risk infants who receive breastmilk obtain all of the protective effects previously mentioned for healthy newborns and, in addition, very specific benefits have been identified, including protection from necrotizing enterocolitis (Albanese & Rowe, 1995; Buescher, 1994; Gross, 1983; Kleigman, Pittard & Fanaroff, 1979; Lucas & Cole, 1992; Neu, 1996). Another health advantage of human milk feeding for high risk infants is greater enteral feed tolerance and more rapid achievement of full enteral feedings (Armand, Hamosh, Mehta, Angelus, Philpott,

Henerson, Dwyer, Lairon & Hamosh, 1996; Gross, 1983; Simmer, Metcalf & Daniels, 1997; Uraizee & Gross, 1989;). Enhanced retinal maturation and visual acuity are additional benefits of breastmilk feeding (Carlson, Rhodes & Ferguson, 1986; deAndreca & Uauy, 1995; Faldella, Govoni, Alessandroni, Marchiani, Salvioli, Bigbiagi & Stano, 1996; Uauy, Birch, Tyson, & Hoffman, 1990). Reduced risk of atopic disease for infants with family risk histories has also been noted (Chandra, 1997; Lucas, et al., 1992). Enhanced developmental and neurocognitive outcomes have also been documented through recent research (de Andreca & Uauy, 1995; Lucas et al., 1992; Meier & Brown, 1994; Morley, 1996; Pierrat, Eken, Truffert, Duquennoy & de Vries, 1996;).

The nutritional composition of milk produced by mothers for their own premature babies has been discovered to be different from that of mothers milk of full term babies. Special properties of preterm milk and their health benefits have been well documented. The infection protection properties of human milk have been considered a key reason to provide human milk to high-risk infants (El-Mohandes, Keiser, Johnson, Refat & Jackson, 1993; Mathur, et al., 1990; Narayanan, Prakash, Murthy & Gujral, 1984; Uraizee & Gross, 1989;). High risk infants are especially prone to devastating infections such as necrotizing enterocolitis, sepsis, meningitis, respiratory syncytial virus, and rotavirus (Lawrence, 1994). With the major health advantages of human milk feeding in this population well documented through research, it is imperative that breastfeeding in high risk infants should be promoted.

Another significant issue related to the promotion of breastfeeding in this vulnerable population is that of cost. The cost of saving babies requiring intensive care for health problems can be catastrophic. The costs to the United States federal and state

governments, of not breastfeeding, are in the billions of dollars (Riordan, 1997).

Breastfeeding is free. This, in addition to the knowledge that breastmilk will keep infants healthier, can play a part in decreasing costs associated with supporting vulnerable high-risk infants.

Statement of the Problem

Many U.S. mothers may initiate the act of pumping and providing breastmilk for their infants while they are in the neonatal intensive care unit, yet not all are able to maintain their breastfeeding efforts until the time of infant discharge, even fewer are able to breastfeed their infants once they are home from the hospital (Meier, Lysakowski, Engstrom, Kavanaugh & Mangurten, 1990; Meier & Mangurten, 1993). Worldwide statistics suggest that mothers with high-risk infants initiate and sustain breastfeeding at rates lower than those of the general population (Byrne & Hull, 1996; Hill, Ledbetter & Kavanaugh, 1997; Jaeger, Lawson & Filteau, 1997; Lefebvre & Ducharme, 1989; Meier & Brown, 1996; Meier, Engstrom, Mangurten, Estrada, Zimmerman & Kopparthi, 1993; Nyqvist & Ewald, 1997; Simmer, et al., 1997; Yip, Lee & Sheehy, 1996).

Although it is well documented that the nutritional, immunological, psychosocial, and cost-saving benefits of breastfeeding in this vulnerable population are immense, the failure rate is very high. Receiving mother's milk and the health benefits of mother's milk is particularly important for high-risk infants. However, stressors related to caring for high-risk infants, the unstable nature of the infants, the obstacles inherent in the NICU environment, the fear and anxiety level experienced by the mothers especially following discharge from the neonatal intensive care unit (NICU), often interfere with breastfeeding. If these infants do not receive their mother's milk, they do not receive the highly specific

health benefits that breast milk offers. Vulnerable infants with compromised health status at birth, need breast milk the most, yet they are the population who receive it the least.

Duration rates for breastfeeding infants discharged from the neonatal intensive care unit are very low. Investigators have pointed to the drastic drop in breastfeeding rates after infant discharge. However, research addressing the mother's perception of the process of learning to breastfeed a high-risk infant has not been extensive. This process involves working with the infant in the NICU, and it includes the continued efforts of the mother and infant at home in the post-NICU discharge period. Our knowledge base is limited concerning what it takes to achieve breastfeeding under these conditions. Information such as the mother's perceived stressors, barriers, needs, support systems, and resources is needed for the development of specific interventions and community resources aimed at supporting these mothers and increasing the rates and duration of breastfeeding in this special population. This area needs to be investigated more intensively.

Purpose of the Study

In order to help mothers in their efforts to achieve and sustain breastfeeding, it is imperative to gain a deeper understanding of what these mothers are experiencing. Therefore, the purpose of this study is to understand this complicated process from the perspective of the mother. The aim of this study is to understand the richness of the process a mother experiences as she learns to breastfeed her high-risk infant. This process will be investigated from beginning to end, starting when the mother realizes that the baby is in danger and ending when she takes her baby home from the hospital and eventually learns to breastfeed her infant. Grounded theory methodology was used. Concepts and

theoretical linkages will be derived from the descriptions provided by the mothers. These theoretical formulations will lead to the development of a substantive theory concerning breastfeeding the high-risk infant.

Definition of Terms

For the purpose of this study the following terms are defined:

Breastfeeding – Infant receiving any amount of breast milk from the mother at her breast on a daily basis.

High-risk infant - Any infant admitted to the neonatal intensive care unit for a stay of four or more days.

Post-discharge period - The period of the first three months that the infant is at home with mother after release from the hospital neonatal intensive care unit.

Neonatal intensive care unit – (NICU) An intensive care unit in the hospital that admits newborns when they have problems with their health status and require close monitoring and specialized care.

Assumptions

The following assumptions are made for this study:

1. Mothers are willing to reveal true information about their experience.
2. Mothers will be able to provide accurate information despite the passage of time.

Summary

Clearly, there is a need to understand the challenging process as mothers learn to breastfeed their high-risk infants. In order to best help these mothers with appropriate interventions and resources, it is essential that we listen to them describe their experience.

By listening to the experts, the mothers who have lived this experience, the process of breastfeeding the high-risk infant can be uncovered and understood. With this rich knowledge, we can put into action research-based, comprehensive breastfeeding services, to promote the health and well being of this special population.

CHAPTER II

Review of the Literature

Breastfeeding high-risk infants is not simple. It is challenging for the infants, their mother's and the healthcare professionals who care for them. There is a distinct lack of published research about the process that mothers experience when they are learning to breastfeed their high-risk infants. Studies about mothers perceptions of breastfeeding and studies about the unique challenges and stressors facing these mothers of high-risk infants will be addressed. Research on documenting the use of breastfeeding interventions and documentation tools in the NICU will be presented as well as studies concerning the postdischarge period.

Mother's perceptions of the breastfeeding experience

Several researchers have addressed the area of mother's perceptions concerning the breastfeeding experience with a healthy newborn. Gill (1997) used a qualitative design with grounded theory methodology. The purpose of the study was to describe mothers' successful breastfeeding experiences. The researcher interviewed 15 white, well educated, breastfeeding mothers. Five stages in the process of becoming a nursing mother emerged from the data: making the decision, benefiting baby, being encouraged, making it work, and discontinuing. The researcher identified the core category as, the process of being a nursing mother.

Leff, Gagne, & Jefferis (1994) used a qualitative design using techniques of phenomenology. The purpose of their study was to explore successful breastfeeding from the maternal perspective. They interviewed 26 breastfeeding mothers from the WIC program. Analysis of the data yielded five major categories of successful breastfeeding:

infant health, infant satisfaction, maternal enjoyment, desired maternal role attainment and lifestyle compatibility. The researchers identified, working in harmony, as the core concept.

Locklin & Naber (1993) used a qualitative, grounded theory approach to understand the breastfeeding experience from the perspective of the mother. The sample comprised 10 minority, low income women who had breastfed and were acting as breastfeeding peer counselors. The researchers presented in their finding five themes that emerged from the data: against all odds, personal motivation, support, attachment, and telling the world.

Bottorff (1990) used a qualitative, phenomenological approach to investigate the experience of mothers who breastfed when other choices were available. The researcher interviewed three breastfeeding mothers. The findings included a description of the process of breastfeeding from the perspective of the mother and included: deciding to breastfeed, when it is not easy, giving, being committed and choosing a time to stop.

Mothers' perceptions of breastfeeding a preterm infant

One study was identified that addressed mothers' perceptions of breastfeeding a preterm infant. However, two research articles, addressing this study were found. The same sample was used for both. Kavanaugh, Meier, Zimmerman, & Mead (1997) used a qualitative approach with naturalistic inquiry. The purpose of the study was to expand on a theme that emerged from an earlier large study (Kavanaugh, Mead, Meier, & Mangurten, 1995). The theme investigated was, "rewards and efforts of breastfeeding for mothers of preterm infants." A convenience sample of 20 breastfeeding mothers of

preterm infants, at about one month post discharge from level III NICU was used for the study. Data analysis revealed that mothers benefit emotionally from breastfeeding their preterm infant. Rewards were identified as benefits identified for the mothers or their infants: knowing they were providing the healthiest nutrition for the infant, enhancing bonding, perceiving infant contentment, convenience, and giving a tangible claim on the infant. Efforts as presented by the researchers included mothers' lifestyle changes and balancing rewards and efforts.

Kavanaugh, Mead, Meier, & Mangurten (1995) used a qualitative research approach and naturalistic inquiry to describe maternal concerns about breastfeeding a preterm infant in the postdischarge period. This was the original large study. The investigators interviewed 20 mothers of preterm infants from level III NICU. The mothers were white, middle class and received individualized in-hospital breastfeeding support services. The researchers presented three categories of maternal concerns that emerged from the data: adequate milk consumption by infants, milk composition, and problems with the mechanics of breastfeeding a preterm infant.

Stressors in the NICU

Furman, Mercuri, & Hack (1998) examined the rate of breastfeeding among mothers of very low birth weight infants, the correlates of breast milk pumping and transition to nursing at the breast. The sample was comprised of 82 mothers and their 69 singleton and 21 twin VLBW infants. Data analysis from this study revealed that there are multiple, practical challenges that appear to affect these mothers' experiences in attempting to nurse their high-risk babies at the breast. Of the 39 mothers who chose to

pump, 19 were still pumping at NICU discharge and only eight made successful transition to the breast. Mothers who continued to pump tended to be white, married, and older, and their infants had fewer complications. The authors suggest that specific interventions and better support might improve the success rates.

A descriptive study acknowledging the unique stressors associated with having an infant in the NICU identified parental perceptions of stress and coping experiences. The investigators compared differences in parental perceptions of their stress and coping experiences with children in pediatric intensive care units and the neonatal intensive care units. The sample was comprised of 31 NICU and 20 PICU parents. Data analysis revealed that parents in both groups experienced the most stress from alteration in their parenting role. Problem focused coping was identified as being most helpful (Seidman, Watson, Corff, Odle, Haase & Bowerman, 1997).

Winders Davis, Logsdon, & Birkmer, (1996) used a descriptive study design to examine specific types of social support that mothers of preterm infants expected before, and received after their infants discharge from the NICU. The sample comprised 37 mothers of hospitalized preterm infants. According to the researchers, analysis of the data revealed that these mothers of premature babies found that material, emotional, and comparison support were more important than they had expected. The mothers also revealed that they received less support than they had expected. Due to the overwhelming stressors confronting mothers of premature infants and the perceived lack of support the researchers suggest that nurses need to be involved in the follow-up care of these women and their infants. Davis, Logsdon and Birkmer (1996) recommended anticipatory

guidance because data analysis suggested that these mothers were at high risk for becoming overwhelmed once the infant is home from the hospital especially if they were already depressed or if the infant had special needs.

Nyqvist & Sjoden (1993) used a descriptive design to test interrater agreement in classification of mothers' comments and advice, and to structure and interpret this information according to the Roy Adaptation Model and to interpret the theory in the NICU setting. Data were collected from 178 semi-structured telephone interviews of mothers whose infant had been in NICU. Analysis of the data suggested that these mothers felt that the actual physical and psychosocial environment of the NICU was not conducive for breastfeeding. The mothers commented that they felt uncomfortable in the technical and hectic environment of the NICU. The main advice that the mothers offered concerned the need for privacy; to be able to sit and hold the baby, time to get acquainted with baby and breastfeed without being looked at and to be able to express feelings.

Brown, Spatz, Hollingsworth, & Armstrong (1992) did a qualitative study with 20 mothers of low birth weight infants in which they discovered that one of the biggest stressors was the strong fear of whether the infant would survive. This fear of the unknown was found to be emotionally exhausting for the mothers. Other barriers to breastfeeding identified in this study included inadequate information about the benefits of breastfeeding for low birth weight infants, lack of support and encouragement from health care professionals, difficulty accessing milk expressing equipment, inconsistent advice about breastfeeding and lack of breastfeeding assistance from a specialist with expertise in breastfeeding of low birth weight infants.

Breastfeeding interventions and documentation in the NICU

Infants in the NICU are different. They may be immature, weak and / or stressed. The process of breastfeeding these infants is completely different. Kliethermes, Cross, Lanese, Johnson, & Simon (1999) used a prospective, randomized controlled trial to compare nasogastric tube and bottle supplementation as two means of transitioning preterm infants to the breast. The sample consisted of 84 preterm infants. Results indicated that infants who were transitioned with the nasogastric tube were more likely to be breastfeeding at discharge, three days, three months, and six months after NICU discharge.

Baker & Rasmussen (1997) described the implementation of the NICU breastfeeding record at Washington Medical Center NICU. The breastfeeding record was initiated by the lactation consultant in the NICU for all infants of breastfeeding mothers and was used until infant discharge. This documentation tool included basic information about the mother and the infant, teaching checklists, a breastfeeding assessment grid, and a discharge planning information. The investigators noted that this documentation tool provided an efficient and complete method for recording the progress of the mother and infant. Authors proposed the use of this as being helpful in integrating research into clinical nursing practice regarding the care of infants in the NICU that are breastfeeding.

Assessing infant readiness to breastfeed and subsequent effectiveness at the breast is imperative. Nyqvist, Rubertsson, Ewald, and Sjoden (1996) used a nonexperimental design with direct behavioral observation for the purpose of developing a clinical tool for observing breastfeeding in the preterm infant. A convenience sample of 25 infants, 12 full-

term and 23 preterm infants were used. Data analysis led to the development of a tool named the Preterm Infant Breastfeeding Behavior Scale (PIBBS). The researchers suggest that this tool was found to be effective when used by neonatal personnel and mothers to describe developmental stages in preterm infant breastfeeding behavior. It is suggested that the scale showed good capacity to discriminate between infant gestational ages and can be used for helping mothers identify their infants emerging competence.

Information given to these mothers needs to be specialized. Meier et al. (1992) used a naturalistic design with participant observation. The purpose of their study was to describe a model for providing breastfeeding support in the NICU. The sample consisted of 132 mother-infant pairs from a level III NICU. All the mothers had initiated lactation efforts. The researcher made note of the fact that many times breastfeeding information given to these mothers may be inappropriate, inconsistent, or lacking. A research-based model for providing breastfeeding services in the NICU was created from data obtained in this study. Specific interventions within this four phase model included expression and collection of mother's milk, gavage feeding of mother's milk, in-hospital breastfeeding, and postdischarge breastfeeding management. A central feature of this model was that a nurse or physician, with expertise in both lactation and the care of the high-risk infant, coordinates breastfeeding services. The researchers suggest that educative and technical breastfeeding support is necessary in order for mothers to provide their high risk babies their milk.

Breastfeeding of high-risk infants after discharge from the NICU

Supporting mothers and infants in the post discharge period continues to be a serious concern and a challenge. Without intensive support at home, these mothers become overwhelmed and discouraged. Many abandon their breastfeeding efforts and then both mothers and infants lose the benefits of breastfeeding

Hill, Ledbetter, & Kavanaugh, (1997) used a prospective descriptive design to examine the feeding patterns of low-birth-weight infants on the day of hospital discharge and four weeks after birth. The sample consisted of 110 mothers who intended to breastfeed their low-birth-weight infants. After data analysis, the researchers suggested that mothers of infants discharged from the NICU benefit from “anticipatory guidance”. The researchers propose that mothers should be provided with accurate information concerning the range in feeding patterns that might be expected after discharge. These include, not being able to consume entire feeding at breast, and the use of complements. The investigators stressed the point that adapted definitions of breastfeeding for this special population need to be explored. In addition, the need for continued support and assistance in the early discharge period was identified.

Shapiro (1995) used an experimental design to demonstrate that with adequate community based supports in place, most low-birth-weight infants could be discharged from the NICU earlier and safer. A randomized trial was implemented. The control group consisting of 47 mothers of low-birth-weight infants continued to receive routine medical and nursing care. The experimental group consisting of 48 mothers of low-birth-weight infants received early discharge with community follow up. The researchers

suggested that community based programs that provided individualized education and support were cost effective and safe. The researcher also noted that results of this study indicated, one of the most identified needs made by the mothers was assistance with breastfeeding.

Summary

This review of the literature reflects the research that has been done addressing this special population in relation to breastfeeding. There is a lack of research in the specific area of mothers perceptions of the breastfeeding experience with high-risk infants. Qualitative studies have been done on this process from the mothers' perspective in well newborns. However, the process is different in many ways for a mother who must artificially induce a state of lactation and sustain it until her baby is strong enough to come to the breast. The separation of mother and infant is another significant difference. Some qualitative researchers have focused on this process with premature infants, however, not all infants admitted into the NICU are premature. Several quantitative studies have been done to explicate specific models of care for the mechanics of breastfeeding in the NICU. Documentation of specific interventions and infant assessment and progress with breastfeeding in the NICU has also been tested through research. Through several studies, the post discharge period has been identified as a time when mothers do need help with their infant and breastfeeding. There have been recommendations made from researchers in this area urging the need for more exploration, especially in the post-discharge period. From this review of current breastfeeding literature a gap has been identified as perceptions of this challenging process. A richer understanding of this process will reveal

information for directing appropriate education and support to assist these mothers both in the NICU and in the community after discharge.

CHAPTER III

Methodology

Research Approach

Grounded theory methodology was used for this qualitative research study. The experience that mothers have when they breastfeed their high-risk infants was investigated. Useful theory grounded in the lived experience, is derived from the data when using the grounded theory research process. Grounded theory is the method of choice when little is known about the area of concern (Glaser & Strauss, 1967). Due to the limited amount of research-based knowledge concerning mothers' perspectives of the process of breastfeeding their high-risk infants, grounded theory methodology was deemed most appropriate to meet the objectives of this research study.

Setting

The large metropolitan hospital used in this study as the site is located in a southeast county of Florida. Florida is the fourth most populous state in the nation; the county in which this research was performed constitutes 17 % of the total Florida population and occupies an area of 1,944.5 square miles. This county is almost exclusively urban and suburban with only 22,335 of its total residents (1.2 %) living in the agricultural region located in the far south portion of the county (Florida Health Councils, 1996). The population of this county is culturally diverse. A description of this county by race reveals, 73% White, 21% Black, 0.2% American Indian, 1.4 % Asian/Pacific Islander, and 5% Other (Florida Health Councils, 1996). A continually increasing Hispanic immigration is a defining element of this population. In 1990, 49.2 % of the

county's resident population was of Hispanic origin and by 1996 the percent had grown to 53% (Florida Health Council, 1996).

Site

The site used for this study was a private, not for profit institution in the metropolitan area in Dade County, Florida. This not for profit hospital had 4116 deliveries in 1999. There is an active 12-bed level II and 7-bed level III NICU. In the 3rd quarter of 1999, the level II unit had an occupancy rate of 134.9% and the level III unit had an occupancy rate of 55.4% (Florida Health Council, 1999). Sometimes, level III beds are used for level II patients. Many of the local hospitals transfer high-risk infants to this NICU. There is also a transitional special care unit at this hospital with four beds that acts as an overflow unit. When the NICU is filled to maximum capacity, the transitional unit is opened, and the most stable infants are transferred there.

Sample

A purposive sample of 20 breastfeeding mothers, with diverse cultural backgrounds, whose babies had been discharged from the neonatal intensive care unit, was used in this study. The mothers were currently breastfeeding or, in the past three months, had breastfed their high-risk infants. The infants had been discharged from the NICU after a stay of four or more days and were breastfeeding on a daily basis.

Protection of Human Subjects

Approval from the Behavioral Sciences Subcommittee for the Protection of Human Subjects in Research at the University of Miami was obtained prior to initiation of the study. Site approval from the Baptist Hospital of Miami Research Council was also obtained. A representative of Baptist Hospital contacted prospective study participants

initially. At this contact they were given information about the purpose of the study and method of data collection. They were then asked if they would be interested in participating. If they verbalized an interest in participating they were informed that the investigator would contact them to schedule an appointment for a telephone interview. At the time of the telephone interview the participants were informed of the purpose of the study, the procedure for data collection, risks and benefits, and confidentiality. Informed consents (Appendix A) were obtained verbally before the interviews. Participants were then mailed two copies of the consent form and an envelope with postage addressed to the investigator at the University of Miami address. Participants were asked to sign both copies of the consent form and to return one of them in the envelope provided.

Confidentiality was maintained in the strictest manner as follows:

1. Participants, and the transcriptions of their interviews, were referred to by code numbers. The participant's names that matched the code numbers given were stored under lock and key in a file that only the investigator had access to.
2. All but five interviews were transcribed by the investigator. A medical transcriptionist student who had absolutely no knowledge of the identities of the participants transcribed the five not done by the investigator.
3. XXX's were used in place of any identifying names or places in the transcriptions.
4. Notes and memos did not identify participants by name.
5. In reports of the data no names or identifying information were used so as to provide anonymity.

Participants were made aware that the interviews would be audio taped and transcribed. They were also informed that they could refuse to answer any questions that

they did not want to answer, that they could discontinue participating at any time, and that their participation was totally voluntary. Participants were also informed that there would be no risks associated with participation and if they wanted to discontinue participation there would be no negative consequences.

Sampling Procedure and Data Collection

The breastfeeding census reports from the hospital lactation department were used to identify names of infants who were in the NICU and who were receiving breast milk. Prospective participants who met these eligibility criteria were contacted via telephone, by the lactation consultant at Baptist Hospital. This initial contact, performed by the hospital consultant, was to obtain the mothers consent to be contacted by the researcher. After the eligible participants gave consent to be contacted, the researcher telephoned them, informed them of the study, and asked them if they would like to participate. After the eligible participants agreed to participate in the study, a date was set for a telephone interview.

Open-ended, interactive, telephone interviews were conducted to obtain data concerning the experience of breastfeeding an infant who had spent four or more days in the NICU. The principal investigator conducted all of the interviews. Informed consent was obtained verbally and then followed up with written consent. (See appendix A for informed consent form) An implicit assumption was that the mothers interviewed would be able to provide a description of the process of breastfeeding their high-risk infant. Hence, the data would reflect reality, which would increase the validity of the findings from this study.

A demographic questionnaire was used at the beginning of each interview to obtain basic information such as age, income, cultural background, infant date of birth, infant sex, gestational age and weight at birth, NICU admission diagnosis, days spent in the NICU and past history of breastfeeding (See Appendix B). During the telephone interviews broad questions were used to elicit optimal narration of the mother's experience. The investigator utilized an interview guide in the early interviews. (See Appendix C) This contained six basic questions and was only used as a guide. The questions focused on the mothers perception of the birth of her infant requiring special care, her impressions of the NICU, perceived supports and barriers to breastfeeding while the infant was in the unit, and feelings associated with the process of breastfeeding her high-risk infant. Twenty breastfeeding mothers with high-risk infants discharged from the NICU were interviewed for this study. The average interview time was 55 minutes, although the interviews ranged in time from 25 minutes to two hours. Four of the mothers were interviewed a second time to expand on information that they had provided in the first interview. These second interviews ranged in time from 5 minutes to 30 minutes.

Data collection was controlled by the emerging theory. Questions used in the interviews were modified, as deemed necessary, to test the hypotheses that arose as the data were simultaneously collected and analyzed. Theoretical sampling techniques were implemented. Participants were chosen to enrich the data and meet the theoretical needs of the study. Theoretical sampling is based on the need to collect more data to examine categories and their relationships to assure representativeness (Glaser & Strauss, 1967).

All interviews were tape recorded and transcribed verbatim immediately to ensure accuracy of the spoken word. The transcriptions included emotional descriptions in

parenthesis when appropriate such as, mother crying, sighing, giggling, etc. This was done in an attentive manner to capture the nonverbal communications that added depth to the data. The investigator also took notes of key points, mother infant interactions and household activities that took place during the interviews. These notes were then added to the written transcriptions.

Data Analysis

Data obtained from the demographic questionnaire were quantitatively analyzed to yield percentages, means, modes and ranges. Interview data were analyzed with data collection as per the techniques of grounded theory (Glaser & Strauss, 1967). Collection and analysis occurred simultaneously. The analysis began immediately after the first interview had been transcribed. Coding procedures were utilized. Coding represents the operations by which data are broken down, conceptualized, and put back together in new ways (Strauss & Corbin, 1990). The purpose of using these analytical procedures is to discover rich, parsimonious, explanatory theory that closely approximates the reality it represented. Data were coded using constant comparative methods. Participants' experiences were compared. The "raw" data were broken down and examined word-by-word, and sentence-by-sentence. Significant phrases and words were identified and highlighted. Questions were asked of the data such as, "What is this?" "What does this mean?", and each discrete incident, idea, or event was given a label to denote a category. Each incident of the data was coded into as many categories of analysis as possible, as categories emerged or as data emerged to fit an existing category (Glaser & Strauss, 1967).

Categories emerged and were either constructed by the researcher or abstracted from the language of the research participant (Glaser & Strauss, 1967). For example, "Keeping a close watch", was a named category taken from the transcribed words of a mother describing her vigilance over her high risk infant in the neonatal intensive care unit. A basic premise in the constant comparative method of analysis is that when one is coding an incident for a category, one must compare it with previous incidents in the same and different groups coded for the same category. In doing this constant comparison of incidents in categories, the researcher is able to generate theoretical properties of the category (Glaser & Strauss, 1967). Theoretical ideas or insights that came to mind were recorded by the researcher as memos, or theoretical insights and were then referred to when reconstructing the data into the theory. Memos and coding of categories were written on the margins of the actual transcribed interviews. Memos were also written to bracket out any preconceived assumptions of the researcher. Although past experience with the phenomenon being studied can add to theoretical sensitivity it can also add biases. Therefore, the researcher has to be aware of this and needs to bracket out presuppositions.

Data collection and analysis continued until no new categories emerged and the existing categories became fully developed. When this "empirical confidence is reached, the categories will be said to be saturated" (Glaser & Strauss, 1967). Initially, 45 categories emerged from the data. Similarities and differences among categories were identified and refined. Properties of the categories were identified and subcategories evolved. Early in the coding process, there was constant comparison of incident to incident. The procedure then converted to the comparison of incidents with properties to incidents with properties (Glaser & Strauss, 1967). In this way diverse properties started

to become integrated and relationships between categories were identified. A conceptual order became apparent as different categories and their properties become integrated through constant comparisons.

A core category was identified. The core category accounts for a pattern of behavior that is relevant for the participants (Glaser & Strauss, 1967). All other categories are integrated around the core category, which is seen as the main content of the data. It emerges over and over again in every interview.

Memos played a significant role in the generation of the theory. These theoretical insights were reexamined and sorted and served to facilitate generation of the emergent theory. The theory was then delimited to achieve both parsimony and scope. This refers to what was done by reducing terminology and collapsing categories. Each category was evaluated to see if it could be subsumed by another category. The initial 45 categories were collapsed to ten, then eight, then six, and finally five. Categories of higher order were left that subsumed the subcategories and their properties. This refers to what was done so there could be a smaller set of higher-level concepts used in the theory (Glaser & Strauss, 1967). Through this inductive method a substantive theory was developed. An expert in qualitative analysis served in supervision and consultation for coding, analysis of data, and conceptualization of the theory that emerged from the data.

Judging a grounded theory study

An analogy can be made for reliability in a grounded theory study to refer to the ability of the generated theory to work and be useful if it were to be applied to a similar situation. It also relates to the repeatability of the data as it emerges during the simultaneous collection and analysis. As the same concepts emerge categories become

saturated and dense thus increasing reliability. An analogy can be made for validity to refer to the notion that the grounded theory which emerged from the data must “fit” the phenomena under study (Glaser & Strauss, 1967). This refers to the notion that the categories that are generated must have come from the data and be a true representation of what the reality is. The theory should also be clear with categories that are meaningful and derived from the data. The grounded theory should have the ability to explain the experience under study. Glaser & Straus (1967) in speaking about the truth of a grounded theory process state:

A grounded theory that is faithful to everyday realities of a substantive area is one that has been carefully induced from diverse data, and in this way the theory will be closely related to the daily realities (what is actually going on) of substantive areas, and so be highly applicable to dealing with them.

Summary

This chapter is a representation of the grounded theory method, which was used as the research approach in this study. The setting, site and sample are discussed as well as protection of human subjects, sampling procedure, data collection and analysis. Criteria used in judging a grounded theory has also been addressed.

CHAPTER IV

Results

In this chapter, the results of the comparative analysis of the transcribed interviews will be presented, and the core category that emerged from the data and its subcategories will be discussed in detail. The process a mother experiences as she learns to breastfeed her high-risk infant will be described from the mother's perspective. Actual statements by the mothers will appear as quotations inserted into the text of this chapter. The demographic data obtained from the questionnaire will be presented as a profile of the participants in this study.

Demographic Data

The demographic questionnaire was used to obtain information about participants in this study. For a brief description of study participants, see Table 1. There was a total of 20 mothers; who ranged in age from 24 to 39 years, with an average participant age of 30 years. All the participants in the study were married. The majority of the sample, 55% was of Hispanic ethnicity, while 40% of the sample was White Non-Hispanic, and one participant, was of Eastern Indian background. Eighty percent of the participants had some college study with 45% having two to four years of college and 35% having graduate level education. Twenty percent of the participants had high school education only. Family income was represented as follows: 45% had income levels of \$30,000 to \$50,000 a year and 55% had incomes greater than \$50,000. Forty five percent of the participants were first-time mothers, and 55% had previous nursing experience. Complications during pregnancy were broken down as follows: 55% of the participants experienced preterm labor, 20% experienced pregnancy induced hypertension, and 25%

**Table 1: Sociodemographic Characteristics of Breastfeeding Mothers
(N=20)**

Sociodemographic Characteristics	Participants	
	(n)	(%)
Ethnicity		
Hispanic	(11)	(55%)
White	(8)	(40%)
Other	(1)	(5%)
Education		
High School	(4)	(20%)
2 yrs College	(3)	(15%)
4 yrs College	(6)	(30%)
Graduate studies	(7)	(35%)
Yearly Family Income		
30,000-40,000	(5)	(25%)
40,001-50,000	(4)	(20%)
>50,000	(11)	(55%)

reported no complications during pregnancy. The average hospital stay for the participants in this study was three days with a range of two to five days.

For a brief description of the mothers infants in the study, see Table 2. Four sets of twins were in this group of infants. Fifty-four percent of the infants were male, and 46% were female. The average gestational age was 34 weeks and 4 days. Four pounds, eight ounces was the average birth weight. The NICU admission diagnosis was broken down as follows: 70% were premature, 25% suffered from respiratory distress syndrome, and 5% (one infant) was hyperbilirubinemia. The infant's average length of stay in the NICU was 14 days with a range of 5 to 45 days.

The Core Category and Basic Social Process

The core category that emerged from this study was, "Navigating through Uncertainty: Breastfeeding the High-risk Infant". This process emerged as mothers' described their efforts in learning how to nurse their high-risk infants at the breast. Glaser & Strauss (1967) described a core category as "one which accounts for most of the variation in a pattern of behavior, without which the grounded theory will drift in relevancy and workability". A theme that runs through this process from beginning to end is an ongoing sense of threat that leads to varying intensities of fear. The participants shared how they progressed through the different phases of this process and how they eventually learned to become competent and confident and finally reached a point where they were comfortable with breastfeeding. All of the categories, which are abstractions of the phenomena observed in the data, are subsumed by the core category. The process of learning to breastfeed the high-risk infant was determined to be central to the phenomenon under study.

**Table 2: Characteristics of High-risk Infants
(N=24)**

Characteristics	(n)	(%)
Gestational Age		
≤ 28 weeks	(2)	(8.3%)
29-31 weeks	(4)	(16.7%)
32-34 weeks	(9)	(37.5%)
35-37 weeks	(4)	(16.7%)
38-40 weeks	(5)	(20.8%)
Birth Weight		
< 4 lbs.	(9)	(37.5%)
4 – 6 lbs.	(8)	(33.3%)
> 6 lbs.	(7)	(29.2%)
Days in NICU		
5 – 10 days	(11)	(45.8%)
11 – 20 days	(6)	(25.0%)
> 21 days	(7)	(29.2%)
NICU Admission Diagnosis		
Prematurity	(17)	(70.0%)
RDS	(6)	(25.0%)
Hyperbilirubinemia	(1)	(5.0%)
Gender		
Male	(13)	(54.0%)
Female	(11)	(46.0%)

Major Categories in the Process

The core category “Navigating through Uncertainty” consists of five major categories. The process has a beginning, middle and an end. Not everyone passes through these phases at the same rate, nor in the same order, and there is often movement back and forth between the phases. Although the process appears to be linear in nature, it is not. In many instances there is overlap, and sometimes mothers actually return to a previous phase before moving ahead and progressing through this process. The duration and intensity of each phase may vary as a consequence of differences in individual circumstances related to the infants and their mothers.

An outline is presented in Table 3 to identify the taxonomy of the components of the theory that has emerged from the data in this study. The core category is “Navigating through Uncertainty”. The major categories are “Realizing Something is Wrong,” “Enduring the Heartbreak,” “Living with the Changing Reality Day by Day,” “Being a Mother in the NICU,” and “Mothering the Baby at Home.”

The subcategories of each major category, will be discussed including significant cardinal features. Actual transcribed quotes from the participants of the study will be presented as a validation of the components of the process.

The causal event that propels a mother into the process of breastfeeding a high-risk infant is finding out that something is wrong with her baby. This realization acts as the initiation of fear, the overriding emotion that runs through the process in varying intensities. An increasing sense of confidence mediates fear. As a mothers’ competence with the baby increases her confidence grows. Fear decreases to a point that it is not the

Table 3: Taxonomy of Experiences**Core category: Navigating Through Uncertainty**

- 1. Realizing Something is Wrong (initiation of fear)**
 - a. Knowing the baby's life is at risk**
 - b. Seeing baby whisked away**
 - c. Experiencing the beginning of separation**
- 2. Enduring the Heartbreak**
 - a. Relinquishing the care of the infant to the NICU nurses**
 - b. Dealing with a multitude of feelings**
 - c. Taking in the NICU for the first time**
- 3. Living with the Changing Reality Day by Day**
 - a. Keeping a close watch**
 - b. Pumping and Bringing the milk**
 - c. Keeping the Faith**
- 4. Being a Mother in the NICU**
 - a. Learning from the nurses**
 - b. Craving to have contact with baby**
 - c. Feeling judged**
- 5. Mothering the Baby at Home**
 - a. Struggling to breastfeed**
 - b. Seeking out support**
 - c. Reaping the benefits of the breastfeeding relationship**

dominating emotion. A feeling of calm takes over, as a mother is able to move past the fear. At this point the mother can begin to enjoy the baby and the breastfeeding experience.

Realizing Something is Wrong

Realizing Something is Wrong begins when the mother finds out that something is wrong with her baby. This category includes the following subcategories, knowing that the baby's life is in danger, seeing the baby whisked away, and experiencing the beginning of separation. Conditions influencing this category are the severity of the infant's problem and the mother's physical and emotional state. This part of the process ends with the NICU admission and the resulting mother–infant separation.

Knowing the baby's life is at risk. For some mothers this awareness of a problem with the infant happens in the prenatal period. In other cases, the mother does not know that the infant has problems until birth. When a mother finds out at the time of birth that the infant has problems, there is no time to come to terms with this information. The mother feels totally unprepared for this situation. In each interview, the mother was able to recall with great detail a distinct moment when she became aware that the infant's life was in danger. Descriptions of this include:

And I knew they had to take her soon because of my high blood pressure but we didn't know how she (the baby) would be, so, I was petrified. They sent me to the hospital and I was scared to death. I was scared for her to be born.

I knew that the babies might be a little bit early. I was having such a good pregnancy so I wasn't worried. But then when my water broke two and a half months early I thought 'oh no this can't be, it's too soon, and the babies aren't ready yet.'

She was coming right on her due date and everything was fine through the whole pregnancy. Then when I was pushing, the doctor told me that the umbilical cord must be tangled up on her because she was not coming down. The doctor gave me

an episiotomy and used the vacuum to get the baby out quick and when the baby came out she had respiratory trauma.

Many mothers imagine the worst, “My water broke and I was hysterical I was crying and screaming ‘oh my God she’s gonna die!’” Another mother stated, “I could imagine that she would have to be ventilated and would have all kinds of problems.” Another said, “It was really awful. I, I, didn’t think he was going to make it. I was really scared.” Another mother recalled her realization at the time of the infant’s birth, “It was a nightmare. The baby couldn’t breathe right and we were believing that he was not going to make it.” Fear is initiated into the process as the mother realizes the baby is at risk. “I was thinking, ‘It’s too early,’ so I was petrified for him,” is how another mother described it. During the realization that something is not right, the element of fear is introduced and uncertainty begins to take on an ever-present role.

Seeing the baby whisked away. After a mother realizes that the baby’s life is in danger, her fear worsens when watching the baby being taken away to be admitted to the NICU. At this point the mother not only imagines that the baby’s life is at risk, she knows it. She sees it. One mother stated:

And as soon as the first baby came out, they took her. I saw her as they wheeled her out in the isolette, then they delivered the second baby and she wasn’t crying...I asked my husband, ‘what is happening?’, and he said that they are working on her...they didn’t even bring the second baby over to me because they had to get her to the NICU right away.

The limited time that mother and baby spend together immediately after the birth is an affirmation that all is not well. “He was having respiratory distress so they whisked him away and took him to the NICU.” Another mother said, “I saw the baby for a couple of seconds. He wasn’t breathing properly and he was too little. They had to put him in the incubator and take him away.” Yet another stated, “We spent no time with the baby right

after the birth. They took her away immediately to the NICU.” This “whisking away” of the baby as one mother put it, is what makes this terrible situation feel very real.

Experiencing the beginning of separation. All the participants in the study were separated from their babies at the time of birth. Some were able to visit the baby later the same day in the NICU, others did not reunite with their infant until the following day. One mother recalled, “They (the postpartum nurses) told me that as soon as I felt better I could go see her, but that she would have to stay there.” Another mother verbalized feeling “very alone” and longing to have the “baby back inside of her.” All the mothers spoke about how they “missed the baby.” One mother shared her experience with the initial separation:

I was so out of it that I don’t even remember what my baby looked like. They showed him to me all wrapped up in this white blanket before they took him away, and all I remember seeing was a big white cocoon. It wasn’t until the next day that I finally got to see my baby in the NICU.

Another mother described, “I decided to go to a breastfeeding class on the floor but I had to leave because I got so upset when I saw all the other mothers with their babies.” At this point mothers were learning that their situation was different from other mothers with normal newborns and they had to learn how to deal with their situation.

Enduring the Heartbreak

This category commences when the infants are admitted to the NICU, and includes relinquishing the care of the baby to the NICU staff and dealing with a multitude of feelings such as sadness, guilt, depression, and grief. This part of the process ends with taking in the NICU for the first time. Conditions affecting this category are the support systems of the mother and the prognosis of the baby.

Relinquishing the care of the baby to the NICU. Each mother knew that the birth of her baby and the events to follow were going to be different than a “normal” delivery and healthy newborn. However, most of them did not realize how different their experience actually would be. The disappointment and pain of having to hand over their baby to someone else was well verbalized by the participants of the study. One mother stated:

I felt kind of frustrated and sad because you know it wasn't like a normal delivery where I could keep my babies and hold them and breastfeed them right away. It wasn't like that at all because they were premature and they had to be taken right away.

Another stated, “It was very upsetting to me because that's all you dream about that the baby will be born and everything will go fine and you latch him on right away and bond in bliss.” Mothers had different reactions to their situations. One mother verbalized this in regards to her babies being handed off to be in the NICU:

That was kind of hard that the babies had to be away from me, I felt sad but I had a sense that they had to be there and they were being taken care of...they (the doctors and nurse) had to do what they had to do. So I guess that wasn't that bad.

This quotation shows the mothers conflict, feeling like they should be doing something to help their babies yet knowing they must relinquish the care of their newborn baby to nurses and doctors in the NICU. Another mother stated, “I knew she was in good hands. I knew I wasn't able to take care of her.” Mothers realized it was necessary for the NICU staff to take care of the baby after the birth. However, this aroused a multitude of feelings that mothers had to learn how to manage.

Dealing with a multitude of feelings. When the infant is born with a condition requiring intensive care, a mother experiences many feelings. “You go

through a lot of emotions.” The birth of a baby is usually a joyous event. In the case of an infant being born with complications this event is somber. Some mothers grieve over the loss of that happy experience. Others, in an attempt to make sense out of the situation, may actually blame themselves. This predicament and the emotional upheaval it creates is something for which many mothers are unprepared.

Mothers shared experiencing many feelings such as sadness, guilt, depression, fear, and helplessness. One mother stated,

The next morning I was crying. I was very depressed. I told the nurse that I didn't even know what my baby looked like. They (the nurses) brought some Polaroid pictures of the baby to my room and I kept those pictures near.

Several mothers described their despair, and said, “I just cried and cried and cried. I cried all the time.”

Other mothers stated they felt “depressed”. Many times mothers verbalized feelings of guilt as they tried to make sense out of the situation and placed blame on themselves. “I was upset and had a lot of guilty feelings, a lot. I kept thinking, “why couldn't I hold onto him longer” (the baby in utero). Another simply said, “I had a lot of guilt on me.” One mother stated:

I wasn't prepared for all of this, and I thought, ‘Oh my God I can't believe this.’ I felt like maybe I could have done something to prolong their birth.

Many times mothers spoke of their feelings of helplessness. “I couldn't hold him, I couldn't do anything for him.” Another stated, “It was horrible, definitely frustrating. I felt like I wasn't even in control of my own child”.

Handling all of these emotions some mothers verbalized that they couldn't sleep because when they lay awake in bed they would worry about the baby. Other mothers

said they felt like they were “in a daze.” One mother stated, “It was so hard for me to process everything. There was so much going on.” However, mothers’ had to learn to deal with these feelings. A shift in focus for these mothers to the reality of the situation and empathy for the baby really developed after the first visit to the NICU.

Taking in the NICU for the first time. Visiting the baby for the first time in the NICU was an experience that each mother could recall with great detail. For some mothers the first visit to the NICU to see the baby was overwhelming and considered by many participants to be forlorn experience. The following statements by mothers in this study demonstrate this.

I didn’t like it at all, it was so depressing in there... all the babies with problems. I looked at my baby and she had all these tubes all over her, and I felt so bad. As I looked at her I was thinking, ‘is she going to make it’ and if she does, what kind of problems is she going to have. I remember being very scared. It’s like you’re going against the unknown.

I was scared and I didn’t feel comfortable there. The baby looked so fragile and helpless and I started crying. I felt like there was nothing I could do to help my baby.

Not only did the mothers observe their own babies, but, many made comments about the environment in general. Some mothers also made comments about the other babies in the unit. In doing this the mothers often made comparisons between their babies and the other babies they saw in the unit.

It was like a beehive. There was a lot going on. I was glad that my baby wasn’t like some of the other babies because there were a lot of sick babies in there. Not that my baby wasn’t sick, but there were others that were worse off.

I thought it would be quiet because you know that is where all the sick babies are. But it seemed so busy and loud. The phone was ringing and people were walking in and out.

Many mothers searched for positive aspects in the NICU. "I felt she was in competent hands and I had good vibes." "The nurses take good care of the babies, and they pay good attention to them in there (NICU)." Another mother stated:

I felt pretty comfortable because my baby was not so little like the other babies. So I thought she would be o.k. It was different in there, not like a regular nursery. It was very dark and quiet because the babies don't cry.

Learning to take in and accept the NICU as the place that the baby will be staying for a while is a necessary step in moving on to living with this changing reality day to day. At this point a mother is taking in the basics. She is learning about the unit in general, where her baby's bed is, when she can visit, who can visit, change of shift, how to scrub, the baby's monitors, the baby's condition, the baby's neonatologists, the baby's nurses, and what can't be touched. This early introduction to the baby's new environment was much to take in for some mothers. Some mothers noticed from the start, "they have so many rules in there (NICU)." In an attempt to cope, many of the mothers initially sought out positive aspects of the NICU, the staff in the NICU and positive characteristics of their babies. An example of such a statement is the following, "The nurses were excellent and they explained everything to me."

Living with the Changing Reality Day-by-Day

When a mother accepts the reality of her situation, she becomes more active in coping with it. This category begins as the mother becomes vigilant, watching the baby and the staff of the NICU very closely. Included in this category are pumping and bringing the milk and keeping the faith that things would turn out all right. Conditions influencing this category are the degree of the mother's persistence and stamina, and strong support systems. An optimistic attitude also influenced how successful a mother

was at learning to cope with changing realities. This category is characterized by a new way of life, consisting of good days and bad days that are taken on one day at a time. The mothers have described it as, "riding the NICU roller coaster." One of the most depressing days for each mother was the day that she left the hospital and had to "leave the baby behind." The following are the mothers' descriptions of that day.

It was awful. I was really depressed and crying. I felt like I was leaving the biggest part of me at the hospital. You always think you're going to go home with your babies. This wasn't the ideal. I missed them so much. I was sad to leave them.

It was the worst day of my life. I bawled all the way home. You know you always have that dream of bringing your baby home with you. You never have the nightmare of leaving him behind. And the worst thing I could ever have done or could ever have imagined doing is what I was doing right then - leaving him, not because I didn't think he was in capable hands, I trusted the nurses... but it was my own selfishness, I wanted him with me. I cried myself to sleep and when I woke up we went right back to the hospital.

It was the hardest thing that I have ever done. I cried the whole way home. I always knew she would be coming home, but the first drive home from the hospital should have been with her. You know and that was hard, very hard.

This new way of life is full of ups and downs. One mother said, "My life totally changed. You have to learn to live with all this unknown, and you become consumed by it." As the mothers soon discover, following the baby's progress is done one day at a time. There are good days, and there are bad days. One of the mothers in the study explained that you have to learn to "ride the roller coaster and realize that there will be ups and downs." Some days the baby makes great strides, and that is a good day. Other days the baby is not doing well, and that is a bad day. Hoping for the best and keeping the faith helps many mothers keep going.

Keeping a close watch. After the initial visit to the NICU, the vigilance begins.

This attentiveness is characterized by the simple act of being by the baby's bedside in the unit whenever possible. "Keeping a close watch" is a mother's words for describing what she is doing. The mother not only watches the baby, but the nurses, the doctors, and anyone who comes in contact with her baby. She makes observations and analyzes what she sees and hears and comes to her own interpretations. One mother stated, "They wouldn't let me even touch him, only they could touch him to do what they had to. I couldn't do anything except sit there and look at him." Another mother shared, "Most of the nurses were friendly, but there were a couple that seemed like they didn't belong there because of the way they were. They were very cold in the way I saw them treating the babies." The vigilance at the baby's bedside was described in great detail by a mother:

If I woke up during the night I would wander over (to the NICU) and peek in at my baby and talk to her nurses. I would go back to my room to sleep but I would pop in again and see her before change of shift. Then my husband would come and we would go together to see her or we would alternate and then we would spend the evenings with her together.

This watch that takes place is the mother's way of doing what she can. "I went to see her every three hours." In the very beginning, when a baby is still unstable, there is little else that the mother is allowed to do. However, this changes as the baby's medical condition improves and the mother soon becomes more active in doing for the baby.

Pumping and bringing the milk. All of the mothers had learned to pump their breasts by at least the second day postpartum. Although some mothers did not enjoy this activity, they did consider it to be something very important that they were doing to help their babies. The following are descriptions of this activity as stated by the mothers.

I felt great to be pumping. I felt like at least I could do something for her. If they weren't going to let me breastfeed her then at least I could help in a way that they were allowing me to by pumping. I was pumping and bringing in this liquid gold. Whenever I got some I would run it over to the unit so she could have it.

I felt so happy to go to the unit in the morning with the milk that I had pumped during the night. I knew it was healthier than formula for the baby, and I felt good knowing that she would be getting my breast milk.

The mothers mentioned the fact that breast milk is better for the babies than formula and that made them feel good. They also had pride because this was milk that only they could provide. "It was like I was finally doing something for them and it was the best thing I could do. It made me happy to be able to do it." The mothers took pride in their ability to provide for the baby in this way. One mother said that bringing the milk to the hospital was "so exciting and it made me feel like a real mother."

Participating in the baby's care in this way was rewarding for many of the mothers.

I felt like I was finally doing something. It struck me, it made me feel like I was part of the team, because I was feeling totally helpless. But just by being able to bring the milk I felt like I had some control over helping my baby.

Pumping did have some aspects that were noted by some to be bothersome. Some mothers complained of pain, the small volume of colostrum in the beginning frustrated others, one mother even said she felt, "like a cow." Quite a few of the mothers described the act of pumping as feeling "unnatural."

I felt good about bringing the milk but I would much rather have had her on my breast. You know it's not the same to just bring it in a plastic bag, compared to having the baby on you.

Pumping and bringing the milk for the baby was viewed as a rewarding activity by all of the mothers in this study. This was a gratifying activity that provided each mother with some control over the baby's care. Bringing the milk boosted their confidence and helped them deal with their feelings of helplessness. Many of the mothers spoke of the frustrations they faced with having little control over anything.

Keeping the faith. It is essential that mothers maintain hope that things will get better in order to survive the stress of mothering a high-risk baby. Seeking out positive aspects of the baby and the NICU staff are ways that mothers manage. Finding sources of strength was important. Many mothers reported that they found support and encouragement from others around them. "My sister had been through this with her daughter so she just kept telling me, 'It's going to be o. k.'". Another mother cited her own mother as being a source of strength. "I really wasn't sure that the baby would make it through, but my mother told me, 'I just know that he'll be o.k. So you need to believe that too.'" Mothers reported that their families were the biggest source of support and encouragement. Comments offered by the family, such as "You're going to make it through this and so will the baby," were common. The mother described the unpredictable nature of this situation and hoped for the best.

You would think that every day they would get better, but in fact that wasn't always the way it went. Some days the babies actually did worse, or one of the babies would do good, but the other one would not be doing as well. Like one night Baby B had three episodes of apnea, and that was scary. It's like you're always on guard and hoping that something bad doesn't happen.

Reflecting on the good days gave the mothers courage. They become energized by good days when they don't think they can bear it anymore. A mother describes a good day.

I went to visit him and I knew he was doing better. The mag (magnesium sulfate) was getting off of him and I knew it. I was so excited, he was waking up. They (nurses) were having a hard time keeping his i.v.'s in him because he'd pull them out and he was squirming out of his hood (oxygen hood). He was a different kid. That was an incredible day. The harder time he gave the nurses the happier I was because I knew he was getting better.

The nurses in the NICU would report to the mothers the daily progress of the baby but as one mother stated, "They can never tell you when the baby will come home. They just say we have to wait and see." This waiting requires extreme patience and strength. One mother put it this way:

If I could see the light at the end of the tunnel it would be easier to deal with all of this. But they can't tell you when the baby will come home, and that made it so hard. The not knowing was so hard to deal with.

Many mothers reported that they "prayed for the baby and that others were praying for their baby to get better soon, too." One mother stated like this, "You have to pray everyday. You just don't stop. When you pray, the baby does better".

This action helped to give them confidence that things would work out. Another mother reported, "I knew he was in God's hands and I believed that he would get better." "I had to keep the faith," one mother reported. Another mother stated:

I just knew in my heart that everything was going to be all right. I felt very much at peace, my faith helped me. I prayed every day. My family prayed all the time. That's where the peace came from, all the prayers.

The mothers stated that many times their husbands acted as a source of strength for them, trying to reassure them that things would be o.k. One mother stated, "I had no

choice. I had to believe that she would get better. The alternative was not acceptable, and I didn't want to think about it."

Interactions between the parents in the unit were a way of giving and also receiving support. Many of the mothers spoke of this type of interaction. They verbalized the perceived support gained from these encounters. This mother stated:

It was friendly in there and I don't mean the nurses, but the other moms and dads. You get to know them because they're in the same boat with you, you know with the kids being in the NICU. Sometimes there is nothing you can do for the babies so you just sit and watch them and then you talk with the other parents. That was very comforting. I think it even helped.

"Keeping the faith" and staying hopeful helped mothers enjoy the good days and cope with bad days. The sense of hope was necessary to survive this experience.

Being a Mother in the NICU

This category begins as a mother becomes very active in caring for the baby in the NICU. A common emotion shared by all mothers in this situation is that of frustration. Included in this category are learning how to care for the infant from the nurses, feeling judged, longing to nurse the baby and voicing needs.

Learning from the nurses. Being a mother in the NICU is not an easy task. Caring for a baby with health problems requires new and different skills that must be learned. Watching the nurses and listening to what they say is one way that mothers learn assessment skills. Beyond diaper changing, mothers must learn about monitors and lines. They must learn about assessment of oxygen saturation, apnea, and bradycardia. It is even essential that they learn infant CPR. The nurses act as mentors. By watching the nurses closely, a mother learns how to assess her infant's well being. The mothers learn about the alarms on the monitors, and how to assess the baby's color and respirations.

“In the beginning, every time the alarms would go off I thought she stopped breathing. Then the nurses taught me how to look at her color and they explained about false alarms.” Another stated, “The nurses explained and showed me how to do everything.”

Another mother described it this way:

The nurses were great with her. They made everything look so easy and they were so quick. They showed me how to do her vital signs and how to measure her stomach while she was in the isolette. In the beginning I felt like I couldn't do it as good as them. They were so comfortable with her and I was so nervous.

In the unit, the typical protocol is to start the infant on a bottle even if the mother had intentions to breastfeed. If the infants were lazy feeders, or they nipped poorly, the infant was tube fed. The following are descriptions about the “tube feedings.”

I would do her vital signs, diaper change, and then I would hold the tube like the nurses showed me. I hated that tube, but that was how she got the milk down. That was the only way to feed her at that point because she did not have a strong suck yet.

She was very weak and was being tube fed. I hated that that seemed like it was over stimulating. They were so concerned with not over stimulating her. I didn't understand that tube feeding. I wanted her on my breast.

The nurses explained to me the reason that she had to be tube fed. You know if she wasn't nipping well. They (NICU nurses) even said I could do it, but I didn't want to. A couple of nights they had to tube feed her and those nights were especially hard...well, I didn't go to visit her if they had to tube feed her, I didn't want to see the tube down her.

One day I went in and expected to bottle feed and they (NICU nurses) were in the process of putting the tube down in her mouth to gavage her and that set me off. I mean I just got very upset. She (the baby) was crying and even though I had seen other procedures, this was a hard one.

Mothering the baby in the NICU environment was different also because it happened exclusively in the hospital setting. The mothers were not in the NICU 24 hours

a day. Leaving the baby behind at the hospital everyday was something that continued to be difficult. “ Sometimes I really hated the visits because leaving was so hard.”

Craving to have contact with the baby. The mothers frequently spoke about their craving to hold the baby close and to put the baby to their breast. This started shortly after birth and became more intense as the infant’s medical condition started to improve. The mothers longed to touch their babies and the inability to do so was especially frustrating. The following are descriptions of this frustration by the mothers.

They (NICU staff) wouldn’t allow me to breastfeed her and that was really hard for me. I felt she wasn’t nipping well because it was the bottle and what she really needed was my breast. I felt if I could breastfeed her she would do better.

There were times when I felt like I just wanted to grab her and take her home. She’s my daughter and I don’t think it was right not to let me hold her. As her mother I should have been allowed to touch her when I wanted to.

I had this feeling that if I could put him to my breast I could make things better. I felt like I could comfort him in that way and that would comfort me too.

I had motherly instincts and he was my child not theirs. It was so frustrating when they wouldn’t let me hold him skin to skin. I felt that doing that wouldn’t hurt him, it would probably just make him better. You know he would feel and hear my heartbeat and he would remember it. I think it would be comforting for him.

I thought once she could suck on a bottle she could suck on my breast but no one suggested it and I never asked. I really think if I could just hold her at the breast it would have helped. And even if she didn’t suck on it well, it’s natural and just her being there would cause the milk to let down. I think that would have been soothing for her.

I desperately wanted to breastfeed her and could never do that so I wanted to do some skin-to-skin with her. I know there’s some research out there about doing that with preemies. I wanted to hold her against my body so bad.

The concept of “touch times” was especially difficult for some mothers to understand. These scheduled times were the only times that the baby could be touched, by mothers and nurses. Touch times limit the amount of tactile stimulation a very sick or

premature baby can have. "Touch times made me crazy." The mothers craved to have physical contact with their babies and these limitations on touch were frustrating. They had to learn to deal with these frustrations. The following are descriptions of this.

I had a hard time dealing with touch times. I have three other kids and sometimes I couldn't get there at the beginning of touch time. I felt the touch time was so limiting. Because of this I didn't feel like there was a bond between us. Touching her more could have helped.

They put these limits on holding the baby and because of that I didn't really bond with the baby in the NICU. I bonded with her once I took her home.

Feeling judged. Mothering in the NICU was always done with others around. All of the mothers spoke about their feelings of being watched and feeling judged. "The nurse was standing over me to make sure I was doing it right, and that was hard because it made me nervous. I wasn't as good at it as she was and that made me feel insecure."

I felt like I was being watched all the time, it made me feel on edge. I just wanted the nurses to go away and leave us alone.

Some mothers spoke of this in a positive way, "I was kind of glad she was watching me because I was so afraid I was going to do something wrong." The mothers continually verbalized this fear of doing something wrong. Some mothers even spoke about doing things wrong and then being afraid that the nurses would be mad at them. The mothers spoke of this fear of scrutiny. Mishaps did happen and mothers feared they would be judged or criticized for their actions. The following descriptions suggest this.

It was an accident, but I pulled out the baby's feeding tube. I just knew the nurse would be mad at me, I mean I was mad at myself. But she comforted me and said it was o.k.

I was afraid to do anything. I was so scared and he was just lying there. He wasn't really fighting or anything. And even with the vent, it didn't look like it was helping him. And I couldn't do anything...just touch his leg. Then the nurse asked me if I wanted to change his diaper. She was right there by my side and silly me, I'm changing his diaper and there I go pulling out my own child's tube.

I went ballistic. I thought I killed him. I know the nurses were about ready to kill me. I cried that whole night.

This concern over being watched is also related to following the rules in the NICU. The mothers verbalized their dislike of the numerous rules in the unit.

There are these time limits on how long you can take for the feeding, and how long you can hold the baby. And if you get there late then the nurses will just start without you, and you can't come at change of shift, they won't let you in.

I didn't feel like I was in control of my own baby. I had no control. It was like I wasn't even considered to be her mother. You know you couldn't go in there and do what you wanted to do for the baby's well being. You had to go by what they said. That affects the bond between you and the child and it's frustrating. All you can do is hope that time goes by fast so you can take your baby home.

I felt like everything was out of my hands. I mean here is my kid in the unit and everything was snowballing. They're doing this and that and I was just watching it go by. I got to a point where I just wanted to scream, 'Hey wait a minute you know I'm his mother, don't I get to have any say in all of this?'

Mothers also felt judged concerning their opinion about breastfeeding their baby.

The following excerpts describe this.

I know they were concerned about the baby, but I felt like they didn't really care about having her on my breast. They were so concerned not to over stimulate her and I don't think that holding her at my breast would over stimulate her. But that's what they (NICU staff) thought.

I put her to my breast and she did great. I was so proud of her and us, but the nurses never thought it was good enough. They would say, 'o.k. now give her the bottle so she can get her feeding'.

My baby, she would take the breast sometimes very well and sometimes she would be still sleepy, but if it was her time to eat they (NICU nurses) couldn't wait. They would just say, 'give her the bottle'. That was frustrating because she had to stay on that schedule. You always felt rushed.

Feeling judged on performance with the baby, thoughts about breastfeeding and following the rules in the NICU made the experience very uncomfortable for the mothers.

Having an opinion about the baby's care and not feeling comfortable to voice that opinion was very real and extremely frustrating for some mothers.

I wanted to breastfeed my baby but no one ever mentioned it. I was just waiting for someone to say something because they knew what was best for the baby. They told me everything else, I just figured they would tell me when it was time. I never did put her to the breast in the NICU. I started when I took her home. I think it would have been better if we started in the hospital though.

I could have used some help while I was trying to breastfeed her in the hospital. I was thinking there was a lactation consultant but I mean nobody ever mentioned it to me that she was available and I didn't really ask about it. I don't know - it just seemed like the breastfeeding wasn't so important to them.

I wanted to breastfeed her in the NICU but the nurses never said I could try and it's probably my fault because I didn't ask. But I didn't think I had the option.

For other mothers who did speak up, they definitely felt that they were being judged for this and they got the feeling that their input was not really valued or appreciated. "I would often wonder what they were saying behind my back because I was really putting up a fight to allow them to let me nurse my baby. I know they thought I was annoying." The following are descriptions of this.

I was on a medication but I had information that it was o.k. with breastfeeding. I should have been able to breastfeed. I felt like I was banging my head against the wall with the nurses. I think they found me to be a bit overbearing because I certainly knew my own mind and I had some facts that maybe some of them didn't have and maybe they were a little bit intimidated. I was responding to them on an intellectual level but also as a mom. And you put those two things together and you get quite a force. I think I put a lot of them off and they didn't want to deal with me.

One day I went in for my daughter's feeding and the nurse already fed her and she gave her formula instead of my milk. That made me so mad and I asked the nurse if she thought my milk wasn't good enough and why didn't she give it to my baby. She tried to explain something and then I started to feel like now she's going to be mad at me and maybe she'll take it out on my baby when I'm not there- like maybe she'll not take such good care of her or she'll let her cry.

I went in to do a feeding and it wasn't my turn to nurse so I had to bottle feed him. I looked at the milk in the bottle and said to the nurse, "This isn't the color

of my milk.’ She said, ‘Oops, sorry’. Things like that would happen and I wonder if they did it on purpose to make me upset. You know to try and get me to stop bugging them about nursing the baby.

I heard the doctors saying something about him eating and starting feedings and I was like, you’re not going to feed him, I want to latch him on! And you know, the nurse I had kind of gave me a little look like she wasn’t too thrilled with the thought that I wanted to breastfeed him.

I was about to take him home and I wanted to see if he would nurse before we left the hospital so I told the nurse that I’m going to wake him and try to feed him before we leave. But she was like no, no, no he’s on a schedule so count your blessings. Then she goes, ‘We fix them, don’t break them.’ What does she think, that I’m going to hurt him, or that I’m not going to take care of him right? That comment still sticks in my head to this day.

I really believed that I would be breastfeeding my baby and I told the nurses about my intentions and they made me feel silly for thinking this. One nurse said to me ‘Don’t get your hopes up. We’ll allow you to breastfeed to comfort you but the baby won’t be able to get enough milk.’ So there was little support for breastfeeding. Even when it wasn’t blatant, there was an underlying feeling that they didn’t think it was important.

One mother stated, “I look back on the whole situation and it was so darn frustrating. You are so powerless.” Mothering in the NICU is difficult, but it is the only option these mothers have while the babies are still in the hospital.

Mothering the Baby at Home

This category begins when the mothers take their infants home from the NICU. This category includes struggling to breastfeed, and seeking out support, and it ends with mothers coming to a point where they learn to “reap the benefits” of the breastfeeding experience with their baby. Conditions that affect this category are the tenacity level of the mother, the baby’s health status, support systems and the mother’s ability to seek out necessary resources.

The delayed homecoming of the baby is met with a mix of apprehension and happiness. One mother described the day as “bittersweet”. This day acts as a turning point, a definitive transition from mothering in the NICU to mothering at home.

It was so nice now to have her home. Everything seemed so much more relaxed just not having to run back and forth to the hospital all the time.

I thought it was going to be better. We were so glad to have him at home finally but we had to adjust. The only thing the baby knew was the hospital. He needed patience because at first he cried a lot. He was unfamiliar with this territory. He was used to hearing sirens and monitors going off all the time. So this was very different for him. What I ended up doing was letting him sleep on top of me all the time so he could feel the love.

I had to be slow and soft, you know really gentle with the baby when we brought her home because she was kind of a very nervous baby. I think because of all the stress she had in the beginning. She went through so much so when she came home we made sure we treated her very gentle.

Claiming the infant in this way had tremendous significance for mothers, who could now do what they wanted to with their own babies. “I just held her all day,” one mother stated. Other descriptions of claiming the baby follow. “I was so happy you couldn’t believe. I was like, ‘Oh my God now she’s all mine! I’m in control now. Now I can be her mother’”. Another mother stated it like this, “It was really weird but when I brought her home that’s when I knew she was my baby. Because in the hospital she’s not really yours, she’s theirs”.

Many of the mothers described feeling afraid when the baby came home. One of the greatest fears is that something would happen to the baby. Many of the mothers verbalized their insecurities. “I was scared of how tiny she was and I really didn’t know what I was doing, and I was worried about that”.

I was so glad to have them home but it was really scary. Thank God my mom was here. They didn’t have their monitors and I kept thinking, ‘What if they stop breathing?’ I’m not gonna know because nothing’s gonna beep.

Many of the mothers spoke of their fears that the baby would stop breathing. To alleviate this fear the mothers would “keep them in sight” at all times and just “watch them all the time.” Some descriptions of this include the following.

I was worried about apnea so I would time her respirations when she was sleeping to make sure she didn't have a cessation of twenty seconds or greater. It was never twenty seconds. So that kind of relieved my fears, but the thing about it was that it was my own insecurity, not having spent much time with her alone.

I would be looking at her all the time checking to see if she was still breathing. Sometimes I would even poke her to get her to move so I knew she was still alive. I would never leave her alone.

The vigilance taken up by the mothers earlier in this process continued with renewed vigor now that their babies were home with them. An ongoing concern that the mothers had to deal with was whether the baby was getting enough milk.

Struggling to breastfeed. Only three of the mothers interviewed were exclusively breastfeeding their babies at the time of discharge. Most of the mothers were still performing a juggling act which consisted of putting the baby to breast, pumping the breasts and then complementing the feeding with expressed milk in a bottle. Other time-consuming tasks involved in this course of action were cleaning the pump equipment, sterilizing bottles, storing the milk, warming the milk and preparing the bottles. The mothers learned that managing this repertoire of activities was not easy. One of the mothers described this as her “struggle to breastfeed the baby” and verbalized that it was “all-consuming and frustrating.” The following are some descriptions of this struggle.

I try to latch him on and it gets really frustrating. Sometimes I feel like giving up, especially when he can't do it and he starts crying. I really need to keep my patience and try to help him. And if he can't do it then I go downstairs and put the milk in a bottle and give it to him that way.

I was worried about her getting too tired while trying to nurse and then not getting enough nourishment. So I would try nursing for a little while and then I would go ahead and give her a bottle of my milk, and I think that, you know, that made it very difficult. Um, because I still had to pump, so I would work around her schedule. I was pumping while she was sleeping, so I could feed her as soon as she got up. I tell you I was so busy.

I wasn't sure what to do so I put him to the breast and I'd help him with the suction by moving his chin. And then he would start taking it, but then he would stop and then I would move his chin again then he'd start again. But then it's a process that takes about a half an hour and then I would supplement him with the bottle to make sure he's had enough. And I never knew how much he got from the breast and how much to give him in the bottle so it was very confusing and very frustrating.

I would try to breastfeed one for about fifteen minutes, then if she doesn't take it then my husband would take that baby and bottle feed her while I would try to nurse the other one. Um, and then again I would try nursing for about fifteen minutes and then I'd end up having to bottle feed her and then I'd end up having to pump after that. So the whole process takes between an hour and a half to two hours. And then I'd have maybe two hours before I start all over again.

Many of the mothers explained that they gave supplement to the baby even when the baby nursed well because they were afraid that the baby wasn't getting enough. They wanted to breastfeed but not at the sacrifice of the baby's health. One mother stated:

You know breastfeeding is important to me and I am pursuing it with everything I have. But at the same time I want to know that I am not going to be compromising my baby's health by trying to breastfeed her. You know I don't want to cause any harm to my baby by pushing this breastfeeding.

In addition to the breastfeeding efforts which took considerable time and energy, mothers had to take the babies back for frequent follow ups. Bringing the babies back for follow up was time-consuming and added to the mother's busy routine of caring for the baby. Some descriptions of this follow.

We went three times within the first week of being home. We went back to the hospital for blood tests and that would take like half the day. And you know I was always thinking, 'oh my God is she going to be admitted again.' Um... I

don't think I could have handled that after having gotten her home to have her back in the hospital. That was so stressful.

We took them home on Friday, and Monday the pediatrician wanted to see them. You know it was so important that they gain weight every day. When they were in NICU you know that was a big thing. So the pediatrician wants that too, so in the beginning we were taking them in twice a week for weight checks. That puts a lot of pressure on you. So if they take the breast fine but we still give the bottle so they get more milk.

Another effort for mothers in struggling to breastfeed is keeping up the milk supply as this mother describes, "It was scary in the beginning when I brought him home because I thought I lost my milk, and I thought he was not going to get enough from me."

Some of the mothers shared that they were tired, frustrated and upset and that affected the amount of milk they pumped out. Sometimes a dwindling milk supply caused mothers to give the baby formula. "I knew that giving the formula would decrease my supply even more but what are you going to do the baby needs to eat."

Patience, coupled with a strong will, was necessary, to make breastfeeding work for these mothers and their babies. "You have to really work on it and you know be persistent. You cannot just give up so easily."

Seeking out support. The mothers eventually got to a point where they felt they were unable to continue their breastfeeding efforts without help. At that point they sought out support. For some of the mothers, a family member or friend provided the necessary support. In other cases, the mothers sought out the professional support of a lactation consultant. Many of the mothers spoke of the support that their husbands provided. For example, "One day I was trying to breastfeeding and it wasn't working and you know I started crying and my husband said, 'It's o.k. It's gonna work.'"

My husband definitely helped me. He was very, very supportive with the breastfeeding and I think if he wasn't supportive, I probably would have given up. You know because there were times when I would breastfeed and then just cry because I was in so much pain and I was frustrated and I was tired and I didn't think I was making the milk and I would just sit there and cry and he would say, 'It'll be o.k. You're doing such a good job,' I know that definitely helped.

My husband was without a doubt a tremendous support. He really helped me to persevere. There was one night when the baby was having a growth spurt and he nursing constantly and nothing was coming out of my breast and it was the middle of the night and he was crying and hungry and I asked my husband if I should get the formula and he said, 'No don't do that you'll ruin everything.' I thanked him a week later.

Those who sought the help of a lactation consultant also felt supported. Seeking out much needed support helped the mothers with their breastfeeding efforts. The following quotations from the mothers illustrated this.

I saw in the paper that there was a breastfeeding workshop. I told my husband, 'I want to go to that' and he said, 'I think that's a really good idea, someone there can probably help you.' And that's when I met the lactation consultant. I made an appointment with her and she was a great help. She showed me how to latch them correctly and how to tell if they are suckling properly. She had a scale and she was able to weigh them before and after they ate and we could tell how much they took from me. The first baby after a little while she had gained like one ounce, which she eats two ounces at a feeding. We put her back to the breast and she took some more and we put her back on the scale and she had taken two more ounces! She was satisfied and it was great to know how much she took. My other baby she suckled for a little while but she doesn't get as much so I had to give her some supplement.

I knew that I was going to be successful at breastfeeding as soon as she (lactation consultant) came into the picture. I knew I had the support at that point. My whole mental outlook towards breastfeeding improved, and I think that was a point at which everything started getting better.

You need the support, you need the help. And it's all well and good to have a spouse who's behind you 150%, but in terms of the mechanics of it, the how to's, you need help. That's why it's so important to look to the services of a professional, a lactation consultant, I hate to think where I would be without it. I probably would not be breastfeeding.

One of the mothers commented how she saw the lactation consultant more than once. She states, "We went to the Lactation Center whenever we were having problems or when I wanted to know how much he was intaking. And I knew he was getting adequate milk by the scale". The use of equipment such as scales help mother to determine how much milk transfer was taking place during breastfeeding. Having this information helped mother to determine how much supplementation to give the baby, if any. These efforts required patience and perseverance. The mothers learned to "persist with patience" and to seek out support, and this saved them from giving up.

Reaping the benefits of the breastfeeding relationship. Eventually the mothers reached a point where they learned to be comfortable with breastfeeding their babies. Some mothers were at this point soon after bringing the baby home. These mothers were those who started breastfeeding their babies in the hospital. Many of them had contact with a lactation consultant before the baby was discharged. For other mothers, getting on track with breastfeeding didn't happen for three or four months after the baby's discharge. Coming to a point where breastfeeding becomes enjoyable happens only after mothers learned to feel competent about the mechanics of breastfeeding. At this point, they feel confident that their babies are thriving on their milk and that the babies enjoy being put to breast. It is necessary for mothers to see evidence that the breastfeeding is working.

I know he is benefiting from the breastfeeding because he thrives on the milk. He is healthy and he isn't behind developmentally. He also thrives on the attention and the nurturing. He looks up at me and caresses my face when I am feeding him. I know he feels the love.

He latches on right away without crying and he suckles strong. I feel the pulling, and when I take him off the breast to take his gases out I see the milk coming out of my breast. When I see that I know I have good milk.

I know he is getting enough milk because he is growing and he looks much better, like a normal baby. He is more normal now, you know he wakes up and opens his eyes and he eats every three hours, so now I feel more calm with him.

When he is eating and sucking the milk, my breast is like hard and when he is finished it gets soft again and he is satisfied. That's how I know he is doing it right. And that makes me feel like I'm doing it right too.

When the mothers begin to feel an increased sense of confidence that their babies are thriving on their milk, they are then able to move past the persisting fears associated with the safety and survival of their babies. When fear is no longer the dominant emotion, mothers learn to enjoy their babies and “reap the benefits” of the breastfeeding relationship. One mother stated the following:

Unless you have experienced it, you probably could never explain it to someone in terms of the benefits you reap. It has bonded my baby and I. I don't know if that's even a strong enough word, because we are crazy glued together. It's the moments that I don't know if I could have achieved with her in any other way.

He was his first month of life without his mom, because I was only there a few hours a day spread out. The breastfeeding helped us to bond and it really helped to make up for lost time. Breastfeeding him was the most that I could give him and for me that's what being a mother is all about. I know it has paid off not to give him a bottle because anyone can give him a bottle but I can do more than that.

Mothers also shared feelings of pride when they arrived at the point that things were going well. “When I breastfeed now, oh, it's such a feeling. Like wow, I got the milk and he takes it well and he's going to be fine and grow to be a very healthy boy.” Another mother described the benefits she has experienced from breastfeeding: “When I hold him at my breast I just look down at him and he looks so comforted, and I feel this incredible bond with him. It's such an awesome feeling”. The following is a description by a mother of getting to that point of “reaping the benefits” with her twins.

It was a process that we learned together. I know they did have to learn and I had to learn as well. My babies, maybe because they were premature or maybe because the first thing they got was the bottle, they didn't get the breast right away. But it was a process that happened slowly over time and then boom, we got it. Now it feels great. It's the absolute best nutrition for the babies. It means me giving them the best thing for them and it's more than that too. It's a closeness, it's a bond that only I have with the babies, and you know it makes me feel so good.

Summary

The central phenomenon under study was the process a mother experiences as she learns to breastfeed her high-risk infant. The grounded theory emerged from the data to explain this process. The core category derived from the data, "Navigating through Uncertainty" (See Figure 1) gives an overall description of how mothers view their progression through this experience. A mother described this as "a process that happened slowly over time". It was also described as a "process that they learned together with their baby". Mothers viewed this experience as "scary and full of unknowns". Other mothers verbalized how difficult it was because they "didn't know what to expect day-to-day" and they really could not "see a light at the end of the tunnel". Tolerating the ambiguity was uncomfortable for the mothers but very characteristic of this process.

When a mother realizes that something is wrong, the challenges of breastfeeding a high-risk infant begin. This realization may occur during the mothers' pregnancy especially if she was facing complications herself. For others however, this may not occur until after the baby is born. Soon after the mother realizes something is wrong, even if it is at the time of birth, the mother faces the reality that the baby's life is at risk. Mothers verbalize at this time that they feel "scared to death". They must face the uncertainty of not knowing what will happen next. The belief that the baby's life is in

Navigating Through Uncertainty: Breastfeeding the High-risk Infant

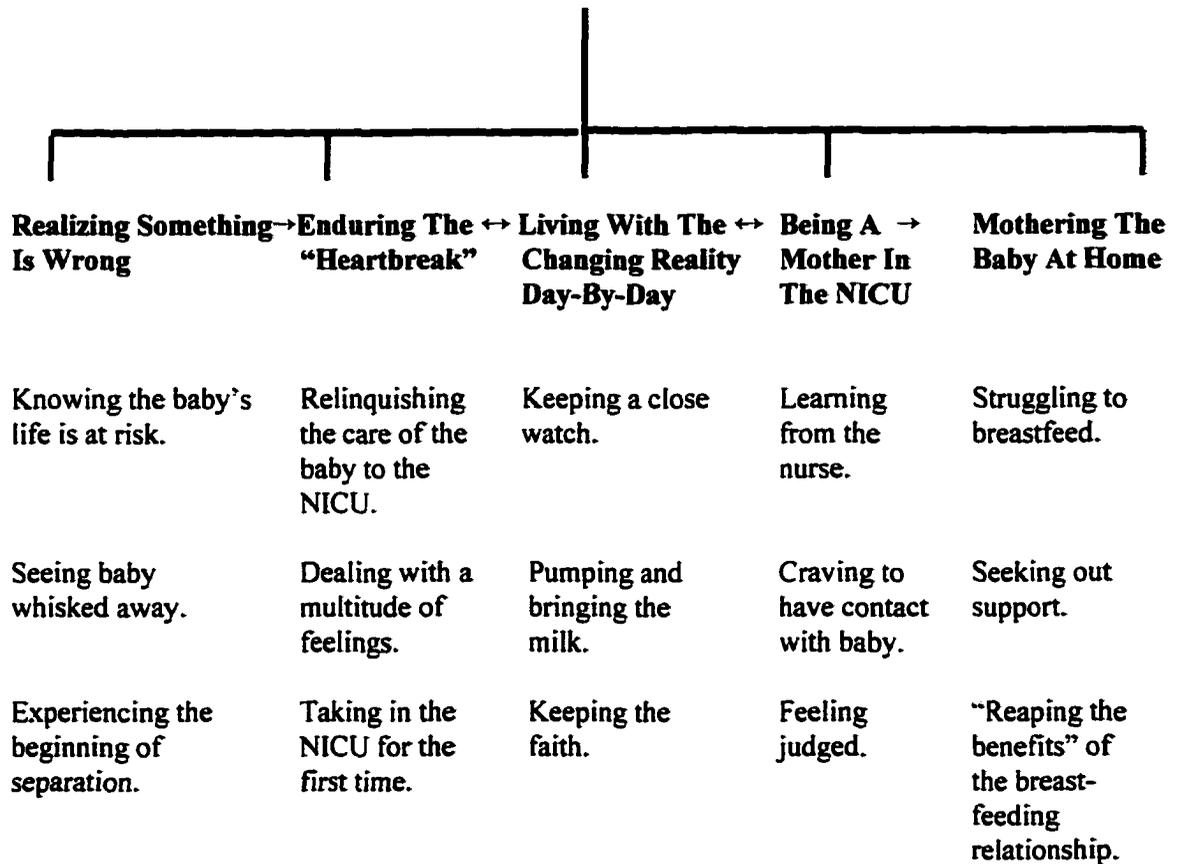


Figure 1. Diagram of breastfeeding the high-risk infant.

jeopardy is confirmed when the mother is not able to spend time with the baby after birth and the mother witnesses the baby being whisked away to the NICU. When the baby is taken away the mother experiences the beginning of separation. While other mothers would enjoy cuddling and nursing their healthy newborn the mother of the high-risk infant must learn to live with this reality of maternal-infant separation. These mothers will struggle with “feeling alone” and “missing the baby”. For the rest of the hospital stay these mothers will be in a separate room away from their infants who are in the NICU.

This separation between the mother and infant creates “heartbreak” for the mothers. This is a very different experience than what mothers expect the birth of a baby to be like. They realize that the babies need specialized care that they are unable to provide so the mothers actually have to relinquish the care of the babies to the NICU. This is sad and confusing for the mothers. Many verbalize feeling “unprepared for this”. A multitude of feelings overwhelm these mothers. Some feel “depressed” and others feel “helpless”. Some mothers try and search for explanations to make sense out of this crisis and in doing so place blame on themselves and struggle with feelings of guilt. Learning to deal with this situation, and all the multitude of feelings it arouses, is challenging for mothers and causes great stress. Mothers verbalize being “in a daze” or having difficulty “processing everything”. As the mothers come to a point where they are physically and emotionally ready, they go to the NICU to see their infant. Taking in the NICU for the first time is seen by many mothers to be overwhelming and much more than they expected. Many mothers verbalized feeling “intimidated”, “scared”, and “uncomfortable”

in there. For many, seeing the baby in the unit was a sad experience, although some mothers verbalize feeling very good to see that the baby was in “good hands.”

After the mothers take that initial step of going to the NICU for the first time, they gain realization of this “new way of life”. They realize that things are different for them. A major turning point that solidifies this awareness is the day that these mothers go home without their baby. They are now living with the changing reality day-by-day. Mothers have described this as learning to “ride the NICU roller-coaster”. This sense of not knowing what each day will bring prompts an act of vigilance over the baby. The mothers begin “keeping a close watch”. Visiting the baby, sitting at the bedside, watching the caregivers and calling from home to check on the baby, evidences this. Mothers also become active in doing for the baby by pumping the breast and bringing the milk. This activity is described as “finally being able to do something to help the baby”. Learning to maintain an optimistic attitude and a sense of hope that things will get better are essential. Keeping the faith in this way helps mothers to persist in their efforts through this process despite the unpredictable nature of their situation.

Soon, the mothers become very active in the NICU learning to care for their babies. They learn from the nurses how to do assessments, take vital signs, and activities such as changing and feeding the baby. Many times mothers at this point begin to become frustrated because they want to do more. The babies are becoming more stable and the mothers are becoming more confident, and consequentially the mothers typically crave to have more physical contact with their babies. Many of the mothers desire to put the baby to the breast at this point. This is also a time that many mothers begin to feel judged because the nurses are observing them and critiquing their interactions.

Eventually, the day comes that the infant is discharged from the NICU. Taking the baby home is a point of transition for mothers who move from mothering the baby in the NICU to mothering the baby at home. Once the mothers are home with their babies they struggle to breastfeed. For many the “juggling act” is much more than they expected. Mothers may find themselves still pumping their breasts, offering the breast, and then deciding how much supplement to give the baby. Mothers feel very unsure of themselves and face varying degrees of fear. Initially, mothers attempt to handle this situation by themselves. Eventually, mothers get to the point where they find they can't persist in this challenging situation without support. In seeking out support many mothers turn towards their husbands, other family members or friends. Some mothers seek out professional support such as the services of a lactation consultant. When mothers receive the help that they need, their confidence and competence increases. At this point, fear is no longer the dominant emotion and mothers can begin to enjoy their babies and “reap the benefits” of the breastfeeding relationship. Some of these benefits have been described as an increase sense of bonding and closeness with the baby, a feeling of pride and accomplishment and a sense of “really feeling like a mother”.

CHAPTER V

Discussion

The following chapter is a discussion of the results of this study and their implications. In addition, the substantive theory that emerged from this study is discussed, and implications for nursing theory, research, practice, education, and policy are presented. Recommendations for future research are offered and limitations of the study are acknowledged.

No studies were found that describe the complex and dynamic process of breastfeeding the high-risk infant from the perspective of the mother using grounded theory methodology. All participants, regardless of ethnicity, age, level of education, or amount of family income, described breastfeeding their high-risk infant as a day-by-day process full of unknowns that required physical stamina, patience and perseverance. The core category, "Navigating through Uncertainty" captured each participant's progress as she persevered in this process full of ambiguity to reach her goal of breastfeeding her baby. Categories subsumed under this core category exemplify the various stages in this navigation and include: Realizing Something is Wrong, Enduring the Heartbreak, Living with the Changing Reality Day by Day, Being a Mother in the NICU, and Mothering the Baby at Home.

The process of breastfeeding the high-risk infant was examined in its entirety. As was discovered in this study, learning to nurse the high-risk baby does not begin when the infant comes to the breast for the first time. This unique process actually begins when the mother realizes that her baby is born with a potentially life threatening problem. This realization by the mother often happens long before she actually puts the baby to breast.

A mother's efforts to sustain breastfeeding in the post NICU discharged period is inextricably linked to what she had experienced previously. In every interview, the mother began talking about her experience at the point when she realized something was wrong with the baby. "Realizing Something is Wrong" was therefore identified as the commencement of the process and the first category subsumed under the core category. This turning point is characterized by fear for the baby. Learning to breastfeed the high-risk infant is a process that is fraught with varying levels of fear. As they progressed through this process, the mothers verbalized the presence of fear in various ways in the different categories. Their biggest fear was that of the safety and survival of the infant.

By exploring and uncovering this real human experience, the challenge that these mothers face has been acknowledged and a better understanding of what they are going through has been gained. The findings of this study suggest that these mothers exhibit physical and emotional stamina in their pursuit to breastfeed, and that they face their fears as they persevere. All of the participants were able to seek out support systems and information in order to "Navigate through Uncertainty" to reach the point where they could breastfeed their baby and reap the benefits of the breastfeeding relationship. However, it was noted, that accurate information and support was not always easily obtainable.

The findings of this study have significant implications for the discipline and the profession of nursing. "The challenge today is to translate the knowledge that has been nurtured and grown in the world of scholarship into practice in the world's of nurses' direct experiences" (Cody, 2000).

Significance to Nursing Theory, Research and Practice

The findings of this study have a significant impact on nursing theory, research and practice. The substantive theory that has emerged from this study is a middle range theory that is limited in scope so that it can be used to guide practice in the area of nursing from which it emerged. In addition, this theory adds to the scientific knowledge base of the discipline of nursing, and it reflects nursing's unique contribution to healthcare. The theory presented in the findings of this study emerged through a rigorous research process, and is relevant to nursing because it is grounded in the human experience, and can be used to guide nursing practice. The theory, "Navigating through Uncertainty to Breastfeed the High-risk Infant" provides nurses with a better understanding of the trials and tribulations of an atypical population of mothers as they attempt to nurse their high-risk infants. By having a better understanding of what these mothers experience, nursing practice can be improved. Breastfeeding in this vulnerable population will therefore be supported by evidence-based practice.

Implications for Nursing Practice

Nursing must respond to changing times in health care. Recent advances in healthcare technology have led to drastic changes in the care of infants requiring intensive care after birth. Babies who never would have survived years ago are now surviving and thriving. The gestational age of viability continues to decrease, and the survival rate of premature infants is increasing. There is clinical data related to viable infants at 22 weeks and 401 grams (personal communication, Charles Bauer, M.D., March 24, 2000). There have been tremendous advances in understanding the pathophysiology of the neonate and application of this knowledge into care of the high-risk infant.

Advancements in electronics and biochemistry, new methods for assisted ventilation, and conservation of body heat have made it possible to sustain these infants who are born in a compromised state of health (Whaley & Wong, 1999). The health outcomes of infants born sick or premature are improving. The number of Level II and level III NICUs nationally is on the rise and their occupancy rates are also up (Florida Health Councils, 1997). In Dade county Florida, the documented rate of neonatal level II beds per 100,000 rose from 5.5 –7.49 to 7.0-7.99, in the period of time from 1996 to 1997 (Florida Health Councils, 1997, 1996).

The care of these NICU babies and their mothers is both complex and filled with difficult issues. Mothers are justified in feeling like they are struggling to breastfeed. Results from this study document their struggle as well as the barriers they are confronted by. Mothers are working against insurmountable odds.

The challenge of nursing, as a discipline and a profession, is to continue to meet our societal obligation to provide the best healthcare services possible in a changing world. For this reason, it is essential that research findings be disseminated and implemented. The findings from this study offer significant practical applications. Findings from this study will build upon the existing body of literature used to provide evidence-based care for this specialized area of concern in this vulnerable population.

In order for NICU nurses to meet patient needs, they must understand that their patient is not only the baby in the unit, but the baby's mother and father as well. Results of this study suggest that the parent's needs may be overlooked. NICU nurses are responsible for the intensive care of sick and premature infants. However, the care they provide must be consciously extended to the mothers as well. "Caring" as the essence of

nursing, must not be forgotten even when the hands-on care is dominated by the highly technical equipment and procedures found in the NICU environment. Empathy, a cardinal characteristic of caring, can only be practiced if the nurse can understand the mother's experience. Although these babies can be very unstable and the critical nature of their health status must not be down played, the importance of the breastfeeding element for these mothers and babies must not be lost either.

Findings from this study explicate the mother's perspective of the process of learning to breastfeed the high- risk infant. Several qualitative studies have explored the process of breastfeeding from the mothers' perspective in well newborns (Gill, 1997; Leff, Gagne, & Jefferis, 1994; Naber, 1993, Bottorff, 1990). Only one study (Kavanaugh, et. al. 1995, 1997) has investigated this process with high-risk infants from the mothers perspective. By bringing forth and acknowledging the complex, dynamic process experienced by mothers of high-risk infants, this study helps NICU nurses gain a richer understanding of the mother's experience. Only a mother who has experienced the NICU can fully understand the fears experienced when the baby's life is in jeopardy. Only she can grasp the heartbreak of the mother-infant separation, or feel the pain of helplessness, or the insecurities of not knowing what the next hour or day will bring. The craving a mother feels when she is unable to hold her baby is real as her feelings of frustration and pain.

This study is a beginning tool for understanding this complex, dynamic, emotionally charged process. By demonstrating a sensitivity to a mother's struggle and fear, nurses can be more empathic. In just one moment, a nurse can impact a mother in such a way that she will remember that moment for the rest of her life. Results of this

study suggest that simple gestures and comments from nurses can have tremendous impact. A single comment can make or break a mother's spirit as she struggles to breastfeed her baby. Positive comments that offer praise, encouragement and acknowledgement can build a mother's confidence. The challenge for NICU nurses is to connect with their patients on a level that shows genuine concern. In order to do this they must talk, listen and practice empathy. An environment that is caring and supportive can only be created through this connection between the nurse and the mothers. Only when support of this nature is incorporated into the NICU can mothers benefit tremendously.

Support systems, such as in hospital NICU breastfeeding support groups, would benefit these mothers as well. Findings from a previous study (Davis, et al., 1996) explicated that mothers felt that they did not expect that they would need such a tremendous amount of support. Davis and colleagues also reported that the mothers did not receive the support the needed. As was presented in the findings of this study, many mothers benefited from the mother-to-mother support found in the unit. An organized meeting of these mothers once a week would provide an arena for exchange of information and support. A lactation consultant who is specialized in providing breastfeeding services to high-risk infants could serve as facilitator of the group. With accurate information and support, mothers would be better prepared to navigate through this learning process with their infant without having to face so many unknowns.

An informational manual, provided to all breastfeeding mothers in the NICU would give accurate information concerning what to expect while learning to breastfeed. Building upon previous studies, the importance of providing anticipatory guidance and

making the mothers aware of what to expect, is invaluable (Hill, et al., 1997; Davis, et al., 1996; Kavanaugh, et al., 1995; Meier, et al., 1992). The findings from this study could be organized into a brief brochure that the mothers could refer to for help along the way. By increasing the competency level of the mothers through accurate, up-to-date, realistic information, their confidence level would increase and perhaps their fears would decrease. Research has shown that mothers want to be involved in the care of their infants whenever appropriate, (Kavanaugh, et al., 1997). Involving a mother who is confident and well-informed provides genuine benefits to the mother, infant and nurse. Communication between nurse and mother is enhanced when the mother has a greater understanding of what she is going through, and this leads to a greater possibility of connectedness between the two.

Nurses need to provide mothers with information about available resources, such as breast pump rental stations and available support groups. Nurses must also evaluate the utilization of the provided resources, and offer anticipatory guidance. Nurses are in a position to guide the mothers and their infants through this process, because of their close contact with the mothers. Results from this study demonstrate the struggle mothers face when they go home with the baby. Therefore anticipatory guidance, such as providing information about appropriate community-based resources, is necessary for mothers at this point.

Nurses also need the most up-to-date and accurate information, and educational inservice programs must be provided. It is imperative that findings from this and other studies be disseminated to the NICU staff nurses so that nursing practice may be improved.

Actual barriers inherent in the NICU environment should be explored. Lack of privacy can be addressed with the use of privacy screens or even time off monitors and short periods of time allowed in a separate room for breastfeeding if the baby is stable. The needs of the NICU nurse must also be addressed. For example, adequate support should be in place for these nurses in regards to helping mothers and infants with feeding. NICU nurses care for patients of high acuity level that are unstable and must be alert, on guard, and available for potential emergencies at any moment. It is extremely difficult for them to provide the time consuming individualized and specialized breastfeeding interventions that these high-risk infants and their mothers require. In order to help mothers achieve breastfeeding in the NICU the support of the neonatologists is essential in promoting breastfeeding as feasible given the baby's condition. For example, breastfeeding should be kept in mind as the neonatologists develop the management plan for the infant. This kind of support is essential. Without the support of the neonatologists little can be done in helping mothers with their breastfeeding efforts.

Breastfeeding readiness must also be assessed in the infants. Some infants who are extremely unstable are not even able to intake their mothers milk through a feeding tube. The infant status and the reality of the situation must be considered. Mothers need to be made aware that many factors will influence infant feeding and feeding methods. It is important that nurses help the mothers understand their infants, the oral intake and the need for nurses to set priorities as they care of the infants. This will aid in providing the mothers with realistic expectations. It is also important to emphasize to mothers that this has to be a team effort. The parents, the baby and the provider team all participate in breastfeeding the high-risk infant.

Implications for Nursing Education

Upon reviewing the four most commonly used textbooks for maternal-child nursing in undergraduate programs (Olds, London, & Ladewig, 2000; Sherwen, Scoloveno, & Weingarten, 1999; Lowdermilk, Perry, & Bobak, 1997, Kenner & MacLaren, 1993), it was noted that very little education is offered about breastfeeding the high-risk infant. The authors briefly mention breastfeeding in this population. Less than half a page, is dedicated to breastfeeding in the high-risk infant. The information is focused on the fact that breastfeeding is a good idea and should be promoted, but, does not detail how to do it, or how to support the mother in this learning process.

Basic information on how to support the mothers facing this challenge is vital because this is a process that should not be left to chance. There is a gap in the information being offered in the textbooks that undergraduate nursing students use. The classic pediatric text (Whaley & Wong, 1999) used in undergraduate nursing programs was also reviewed. Again, very little was offered to nursing students on how to provide nursing care in this situation. Nursing the high-risk infant is a completely different process than nursing a healthy newborn. Sustaining an artificially induced state of lactation waiting for the infant to become well enough to come to the breast is very different. Assisting the mother with pumping, establishing and sustaining a milk supply, storing expressed milk, and dealing with special emotional needs of the mother who is doing this because her infant is in need of critical care is very specialized. As the mother begins to put the baby to the breast in the NICU, interventions by nurses become even more specialized. These individualized interventions are based on assessments of infant and mother. Students need to be made aware of this and have access to this information.

Supporting the mother in this situation requires an understanding of the process. Findings from this study could be incorporated into the maternal-child nursing texts. This would allow a nurse to appropriately guide a mother through the difficult process of learning how to breastfeed her high-risk infant. Nursing students need to be provided with this information in their nursing textbooks. Breastfeeding the high-risk infant is a value to informed nurses. Information generated through this research would help students become the next generation of caregivers who provide the best quality of care.

Another implication for nursing education is the continued promotion of a wholistic practice of nursing. For example, nurses should be encouraged to consistently implement modalities and appropriate communication techniques when interacting with patients. The nonclinical needs of the patient are important when providing care. This wholistic approach needs to be reinforced. As results of this study indicate, simple inappropriate comments can be devastating to a vulnerable mother. Enhanced techniques in the use of introspection and reflection will also aid nurses in bracketing out personal biases and opinions, concerning breastfeeding, when interacting with patients.

Implications for Policy

The results of this study demonstrate the struggle of the mother trying to breastfeed her high-risk infant. Breastfeeding the high-risk infant is not simple; on the contrary it is very challenging. As presented in previous research, breastfeeding offers huge benefits to the high-risk infants who receive their mother's milk. These infants are born with a compromised health status therefore, if they are able to obtain extra protection against infections, it is imperative that this be supported. Studies have documented that mothers need greater resources, especially in the post discharge period

when they bring their infants home from the NICU. (Hill, et al., 1997; Davis, et al., 1996; Kavanaugh, et al., 1995). The post discharge period continues to be a major area of concern and needs to be addressed. It is at this point when mothers' efforts are the greatest and they could use the most help with lactation support interventions. It would be invaluable to have follow up lactation services for these mothers and infants. For example a site where mothers could visit to obtain lactation support and services or even services provided in the home of the mother. In the most recent Healthy People document (2000) it is written that, "the underlying premise of Healthy People 2010 is that the health of the individual is almost inseparable from the health of the larger community" and "community partnerships, particularly when they reach out to nontraditional partners, can be among the most effective tools for improving health in communities". The document encourages leaders to develop community programs. Educational and community-based programs and maternal, infant, and child health were identified as two of the 28 focus areas (Healthy People, 2010). Establishing community-based resources and mandated follow-up of breastfeeding mothers whose infants are discharged from the NICU, would be consistent with the goals set up for improving the health of our nation. An opportunity for political action exists. Findings and recommendations from this study and those that have come before, target this specialized group of mothers and their infants as being vulnerable and in need of advocates.

Recommendations for Future Research

A variety of future studies could help fine-tune the breastfeeding experience in high-risk groups. While this study focused on a mother's perceptions of the experience of learning to breastfeed the high-risk infant, it is recommended that a future study

explore the father's perception of this same process. The findings may aid in providing information about spousal support and how to maximize it.

The sample used in this study was a mix of Hispanic and White ethnicity. It is recommended that this process be explored in a sample of mothers of different backgrounds, or in another country to see if there are special cultural considerations.

Another recommendation for a future study would involve implementing a hospital-based NICU breastfeeding mothers support group to explore mother's perceptions of the benefits of such a support group. In addition, change in practice could also be implemented by providing mothers with the manual of information about breastfeeding the high-risk infant and then determining whether this intervention is beneficial.

This study used a sample of mothers whose high-risk infants were all greater than three pounds and greater than 28 weeks gestation. Further research could explore this process in mother of infants of very low birth weight and gestational age less than 27 weeks. This would be a considerably different sample whose needs might vary tremendously from the women in this study, thus resulting in an entirely different process.

The women in this study were all married, well educated and in the middle to upper socioeconomic group. Research needs to examine how mothers who are unmarried, poorly educated and of low income experience breastfeeding the high-risk infant.

Another grounded theory study exploring mothers perceptions of becoming a parent in the NICU with a sample of non-breastfeeding mothers, is recommended.

A qualitative study exploring NICU nurse's perceptions of supporting the breastfeeding mother in the NICU is recommended.

Finally, a phenomenological study examining in depth any one of the categories that emerged in this study, would bring greater richness, and would build on the the knowledge discovered in this study.

Limitations of the Study

The present study may have been limited because of the use of a select sample of mothers. Mothers in this sample were predominantly Hispanic, educated, middle to upper middle class, and married. Therefore, generalization of these findings to all mothers of high-risk infants is not possible.

Summary

In this chapter the results of the study have been discussed, and implications for nursing theory, research, practice, education and policy have been presented.

Recommendations for future studies are offered. Limitations of this study have been acknowledged.

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Appendices

Appendix A
INFORMED CONSENT

Project Title: Sustaining breastfeeding in high risk infants after discharge from the neonatal intensive care unit.

The purpose of this study is to understand what mothers experience when they continue to breastfeed their high risk infants at home, after they have been discharged from a neonatal intensive care unit (NICU). It is hoped that findings from this study will be used to help support the breastfeeding efforts of these mothers and their infants.

If you agree to participate in this study, you will be asked to tell me about your experience of breastfeeding your baby after the baby was discharged from the NICU. Examples of the types of questions you will be asked are, "What kinds of things helped you to continue to provide breastmilk for your baby?" and "What were your thoughts and feelings when your baby was discharged and you were breastfeeding at home?". The interview will take approximately 60 minutes. It will be conducted over the telephone at a time that is mutually convenient for both of us. The interview will be audiotaped and the recorded interview will be transcribed. You may also be asked to participate in a short follow up interview to verify findings. This telephone interview will also be scheduled at a mutually convenient time and will take approximately 10 minutes. Once the study is completed, the tapes will be erased.

There are no anticipated health or social risks associated with participation in this study. You may find that you benefit from talking about your experience.

Your participation in this study is voluntary. You may choose not to participate or to stop participating at any time without penalty. You may decline to answer any question you want to without negative consequences. Your responses to interview questions will be confidential to the extent permitted by law. Your records may be reviewed for audit purposes by authorized University employees or agents who are bound by the same provisions of confidentiality. All interviews will be coded by numbers, not by names, to protect your identity. Names will not be used in the reporting of any information. Any reports written based on this study will be reported as group results.

If you have any questions regarding your right as a research participant, contact Maria Arnold (Institutional Review Board Administrator) at [REDACTED]

You will receive a copy of this consent form. If you have any questions regarding this study, please feel free to contact me at any time. My name is Susan Golembeski, and I can be reached at the University of Miami, School of Nursing at [REDACTED]. I agree to participate in this research study.

Participant

Date

Witness

**Appendix B
Demographic Questionnaire**

Maternal age:

Marital status:

Ethnic background:

Highest level of education:

Employed: FT PT No

Occupation:

Family income: under 9,999
 10,000-19,999
 20,000-29,999
 30,000-39,999
 40,000-49,999
 over 50,000

Number of children:

Number of children breastfed:

Complications during this pregnancy:

Days of maternal hospitalization after birth:

Infant sex:

Gestational age of infant at birth:

Weight at birth:

NICU admission diagnosis:

Days in NICU:

Appendix C
Basic Interview Guide

1. **When did you decide to breastfeed or provide breastmilk for your baby?**
2. **What were your thoughts when your baby was admitted to the NICU?**
3. **What kinds of things did you feel helped you to provide breastmilk for your baby?**
4. **How did you feel when your baby was put to the breast for the first time?**
5. **What kinds of breastfeeding instructions/referrals did you receive when your baby was discharged from the NICU?**
6. **What were your thoughts and feelings when your baby was discharged and you were breastfeeding at home?**
7. **What things would you tell other mothers who are breastfeeding a baby discharged from the NICU?**
8. **Is there anything else that you would like to share with me about your experience that we did not talk about?**