



2013

# A GROUNDED THEORY MODEL OF MOTHER ROLE DEVELOPMENT WHILE IN THE NEONATAL INTENSIVE CARE UNIT

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Kathy B. Isaacs, Student

Dr. Patricia B. Howard, Major Professor

Dr. Terry Lennie, Director of Graduate Studies

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A GROUNDED THEORY MODEL OF MOTHER ROLE DEVELOPMENT WHILE IN  
THE NEONATAL INTENSIVE CARE UNIT

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DISSERTATION

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A dissertation submitted in partial fulfillment of the  
requirements for the degree of Doctor of Philosophy in the  
College of Nursing  
at the University of Kentucky

By  
Kathy B. Isaacs

Lexington, Kentucky

Chair: Dr. Patricia B. Howard

Co-Chair: Dr. Kristin B. Ashford

Lexington, Kentucky

2013

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## ABSTRACT OF DISSERTATION

### A GROUNDED THEORY MODEL OF MOTHER ROLE DEVELOPMENT WHILE IN THE NEONATAL INTENSIVE CARE UNIT

When a woman discovers that she is pregnant, she begins a process of internal work to develop her mother role. This process has been outlined in the literature for the delivery of a healthy full-term baby, however little is known about the process for mothers of medically fragile babies. A threatened pregnancy and subsequent delivery of a medically fragile baby involves a different process of internal work by the mother to prepare for her role. Mothers with a baby in the Neonatal Intensive Care Unit (NICU) experience stress, uncertainty, and anxiety potentially causing a permanent impact on the successful development of her role.

It is the purpose of this dissertation to explore the process of mother role development among those first-time mothers having a baby in the NICU. This study was conducted using a qualitative grounded theory method. Data collection consisted of personal journals, in-person interviews, researcher notes and observation.

The specific aims include (1) describing the disruption in the individual's preconceived idea of being a mother, (2) exploring specific strategies that support the mother in the development of her role while in the NICU, (3) describing the mother's perception of her role during physiologic changes in her baby, (4) examining the mother's evaluation of her mother-role success, (5) developing a deeper understanding of the process of developing the role of mother while in the NICU, and (6) constructing a theoretical model to illustrate the process of becoming a mother while in the NICU.

**KEYWORDS:** neonatal, infant, mother, mother role, NICU

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Date

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*This dissertation is dedicated to my children,  
Tatum Carrigan Isaacs,  
and James Tucker Isaacs,  
proof that dreams really do come true*

## ACKNOWLEDGMENTS

I have learned so much through this experience and would like to thank those directly involved with the success of this dissertation work. First, I would like to thank Dr. Lynne Hall who was instrumental in helping me to navigate my course work through the successful completion of my qualifying exams as my Committee Chair. I would also like to thank Dr. Patricia B. Howard for stepping in as Chair of my Committee and continuing to provide knowledge and guidance for my professional development. Dr. Kristin B. Ashford has my gratitude for serving as co-chair and for being knowledgeable and practical in her suggestions for improvement. Dr. Patricia V. Burkhart, your vast experience added much to the discussions about qualitative methodology and your support was invaluable. I will never be able to thank Dr. Graham Rowles enough for opening my mind and developing my qualitative way of thinking! I have learned such an appreciation of the “art” of qualitative research and look forward to continuing to study the “process” as I move forward in my professional career.

I would also like to thank my family for being my soft place to fall during the challenges of working full time and being in the PhD program. I would like to thank my dad for giving me a work ethic like no other, I believe it is the foundation for why I continue to achieve. My mother has taught me everything I know about understanding others actions and behaviors lending to a feeling of “comfort” in qualitative research. She is the epitome of never letting me waste time complaining, but helping me to make a plan and move forward! To my sister Robin for being my “rock” when I first started my career in nursing and coming to my rescue when I just simply gave her the “look”. To my husband David, I owe much gratitude for believing I could achieve anything I set my



mind to, even when I had moments of doubt. And lastly, to my twins Tatum and Tucker, words cannot even begin to express what you both have given to me. You have been more than I ever dreamed possible. You have helped me grow as a person and as a nurse caring for others babies. I am so lucky to be your mother!

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## CHAPTER ONE

### Developing the Mother Role

#### **Prologue**

During my 28 years as a Neonatal Nurse I have been interested in the concept of developing the mother role while in the Neonatal Intensive Care Unit (NICU). I have spent my career caring for premature babies and supporting the families during a very intensely challenging time. I especially enjoyed working with the mothers by supporting, encouraging and assisting them in caring for and “mothering” their baby. I am still fascinated at the resiliency of the smallest of our patients and feel privileged to care for them and their family.

I learned about preterm labor and having a threatened pregnancy through my own personal experience. I went to a routine visit when pregnant with twins and was told that I was having “uterine irritability” and would need to be admitted to the hospital. I was 26 weeks pregnant and at this time had worked in the NICU for seven years. I knew too well what could happen and the outcomes for 26-week gestation babies. I was placed on strict bed rest and fortunately was able to carry them to almost 35 weeks gestation. My physician told me that I was the “most compliant bed rest patient” he ever had! I had the perspective that 10 weeks of bed rest was easy if it would ensure my babies would be healthy. When I delivered, my daughter was taken to the NICU and my son stayed in the Newborn Nursery. My son was discharged with me, and my daughter was discharged after eight days in the NICU.

I have always felt that my personal experience of a threatened pregnancy and having a baby in the NICU helped me to be a better nurse. I developed a deeper

understanding of what a mother experiences during her pregnancy and while in the NICU. This personal experience, plus my work in the doctoral program have provided the experience needed to conduct a qualitative grounded theory study that examines the process of becoming a mother while in the NICU. This chapter will describe in detail the purpose of the research as well as the background and significance of the research.

### **Purpose**

It is the purpose of this dissertation to explore the process of developing the mother role among first-time mothers having a premature baby in a Neonatal Intensive Care Unit. The specific aims include (1) describing the disruption in the individual's preconceived idea of being a mother, (2) exploring specific strategies that support the mother in the development of her role while in the NICU, (3) describing the mother's perception of her role during physiologic changes in her baby, (4) examining the mother's evaluation of her mother-role success, (5) developing a deeper understanding of the process of developing the role of mother while in the NICU, and (6) constructing a theoretical model to illustrate the process of becoming a mother while in the NICU.

### **Background and Significance**

My initial perspective on developing the mother role while in the NICU is based on the theory of maternal role attainment (MRA) by Rubin (1976). This theory encompasses the transformation a woman experiences from pregnancy through the birth of her full term baby and is expressed in progressive stages of mimicry, role-play, fantasy, introjection-projection-rejection, and identity. In the first stage, mimicry, the pregnant woman prepares for motherhood by seeking information that will ensure a healthy pregnancy and baby. The work involved increases her awareness of self and

others. The pregnant woman evaluates family relationships in the second stage to establish acceptance of her baby. She also looks for opportunities to “role-play,” such as babysitting, during which she can begin to practice mothering. The third stage of fantasy involves observing and role modeling behaviors of other mothers allowing for exploration and “taking in” desired behaviors. This transitions her to the stage of introjection-projection-rejection involving taking ownership of her role as she retains some of the mothering behaviors she determines are acceptable, while deleting more undesirable behaviors. The final stage of identity is integration of the mother role into the woman’s persona allowing her to feel competent, selfless, and confident in her abilities (Mercer, 1985; Rubin, 1976).

Mercer (2004) incorporated MRA theory into her research and further developed the process, eventually renaming it ‘becoming a mother’ (BAM). The stages of BAM use the foundation provided by Rubin but delineate an extension of her research. The first stage of commitment, attachment and preparation occurs during pregnancy and begins the work of the mother to develop her role. The second stage is acquaintance, learning and physical restoration that occurs during the first 2-6 weeks following the delivery. During this stage, the mother begins learning about her baby and how to provide care and comfort. Moving toward a new normal is the third stage and consists of the mother structuring her role to fit herself and her life. The process is complete with the fourth stage called achievement of the maternal identity occurring approximately around the fourth month. She feels competent and confident in caring for her baby and has reached a new normal. The mother’s self-concept continues to evolve throughout the stages of BAM and is not considered a static process.



There are times when a woman does not successfully develop her role as mother. Women can experience delay, difficulty, or even complete failure in assuming the mother role. Contributing factors can be stress, depression, socioeconomic status, relationship with her mother, lack of support, early mother-infant separation, and role strain (Mercer, 2004).

The research of both Rubin (1976) and Mercer (2004) outline the work of the mother from a stable pregnancy through the delivery of a full term baby. This process lacks the ability to address the needs of the mother whose baby is admitted to the NICU. The experience of a threatened pregnancy and becoming a mother of a medically fragile premature baby differs greatly from becoming a mother of a healthy full term baby. The differences can begin during pregnancy. Being classified as 'high risk' may cause the mother to worry about the viability of her baby. This stress and uncertainty can have a lasting impact on the development of the mother role. The differences after delivery are based on the physiologic stability of the baby and the physical environment needed to sustain the life of the premature baby (MacDonald, 2007).

So the question becomes what is known about a mother's experience when having a baby that needs to be placed in the NICU? Researchers have investigated some outcomes of having a premature baby on the experience of the mother. Immediate separation of the baby from the mother after delivery is often the impetus for feeling excluded. Mothers perceive they are on the outside of the premature baby's environment; specifically, they feel marginalized by their limited knowledge and inability to participate in the care of their baby (Black, Holditch-Davis, & Miles, 2009; Fenwick, Barclay, &

Schmied, 2001, 2008; Heermann, Wilson, & Wilhelm, 2005; MacDonald, 2007; Roller, 2005; Wigert, Johansson, Berg, & Hellstrom, 2006).

Lee, Long, and Boore (2009) found that mothers felt completely unprepared for the NICU environment. Medically and technically driven, the NICU can be very intimidating for families. Mothers can experience difficulty focusing on their tiny preterm baby amid all the machinery and alarms (Heermann et al., 2005; Lee et al.). Black et al. (2009) reported that mothers seemed to react by limiting their social network during the acute phase of the baby's admission to the NICU. After this initial phase, the mother gradually begins to incorporate friends and family back into her environment.

Uncertainty of the premature baby's viability can preclude attachment behaviors for the mother. She may keep her distance by not visiting her baby in the nursery or refusing to physically touch the baby, to protect herself from the potential loss. This lack of engagement can have a temporary or permanent impact on the relationship between mother and baby. Encouraging the mother to see the baby early and often helps support the attachment needed to promote a healthy dyad (Bialoskurski, Cox, & Hayes, 1999).

The findings of Bialoskurski et al. (1999) concluded that providing information to the mother regarding her premature baby is critical to the attachment process. This information not only helps the mother understand about her baby, but helps the mother feel included and valued. Researchers found the NICU nurse as key in providing the mother with information about her preterm baby (Fenwick et al., 2001, 2008; Heermann et al., 2005; Hurst, 2001). The mother can feel intimidated that the nurse knows more about her baby's medical issues and personality. Some mothers report the relationship with the nurse as supportive, while others refer to them as the "gatekeeper" of their baby.

The nurse is responsible for monitoring the physiologic status of the baby and determining the amount of interaction with the mother. This can cause the mother to feel frustrated when trying to develop her mother role, especially when certain mothering activities such as diapering and feeding are taken away because of the instability of the baby.

Kangaroo care, breastfeeding, and care giving activities are interventions that help the mother to feel she 'knows' her baby (Fenwick et al., 2008; Flacking, Ewald, Nyqvist, & Starrin, 2006; Hurst, 2001; Johnson, 2007; Roller, 2005; Shin & White-Traut, 2007).

In summary, we know basic information regarding the impact of the NICU on the mother; however, we need a much deeper understanding of her experience. The research conducted for this dissertation will investigate the process a mother goes through to develop her mother role while her baby is in the NICU. Knowledge of the process will help healthcare personnel and mothers of babies in the NICU to understand what they are experiencing and has the potential to lead to interventions that will assist and guide them through the stages of mother role development.

The next chapter will review the literature as it relates to the use of Grounded Theory within the field of Neonatology. Eleven studies will be compared and contrasted to evaluate the quality of the research and the potential impact on the field of Neonatology.

## CHAPTER TWO

### Review of the Literature

While grounded theory has been used in the disciplines of sociology and nursing (Charmaz, 2006), its use in the field of Neonatology is limited. In this chapter, there is discussion of the published literature of studies using grounded theory in the field of Neonatology (Table 2.1).

#### **A Grounded Theory Perspective**

Grounded theory is a qualitative methodology developed by Glaser and Strauss (1967) that is used to explore a phenomenon of interest as defined by an individual or group of individuals for the purpose of theory generation (Cescutti-Butler & Galvin, 2003; Charmaz, 2006). Hallberg (2006) identifies the two main components of grounded theory as use of the constant comparative method and a systematic methodology throughout all stages of research. The process of constant comparison involves continual analysis of new data with previously collected data through coding, categorizing and theorizing (Charmaz).

Additional components of the systematic methodology used in grounded theory research involve purposive or theoretical sampling, development of analytic codes and categories from the data, memo-writing by the researcher, in-depth interviews, observation, work toward theory development during each stage, and a literature review (Charmaz, 2006; Hallberg, 2006).

Medline, PubMed and Google Scholar were searched using the terms “grounded theory,” “neonatology”, “premature infant,” “qualitative methods”, and “mother role”. Medline and PubMed each had approximately 70 hits and Google Scholar had over 6000

hits. After narrowing the results to those studies involving the use of grounded theory, neonatology, and parenting or the mother role, eleven studies met the criteria for inclusion. Ten of the eleven studies reviewed were published between 2001- 2009. No studies were identified from 2009- 2013 regarding the use of grounded theory in Neonatology.

### **Previous Use of Grounded Theory in Neonatology**

Researchers in the field of Neonatology have conducted qualitative grounded theory studies to explore the experience of parents with a baby in the NICU when withdrawing life support from their infant (Armentrout, 2007), assessing nurse competence (Cescutti-Butler & Galvin, 2003), mothering in the NICU (Fenwick, Barclay, & Schmied, 2001, 2008; Flacking, Ewald, Nyqvist, & Starrin, 2006; Flacking, Ewald, & Starrin, 2007; Heermann, Wilson, & Wilhelm, 2005; Lee, Long, & Boore, 2009; Orapiriyakul, Jirapaet, & Rodcumdee, 2007), breastfeeding (Flacking et al., 2006; Flacking et al., 2007), transferring their baby to another institution (Gibbins & Chapman, 1996), and the effects of a prenatal consultation regarding their baby's congenital anomalies (Miquel-Verges et al., 2009).

### **Approaches Employed in Previous Grounded Theory Studies of Neonatal Care**

Purposive sampling was used in the eleven studies reviewed to select participants that would be able to provide detailed information about aspects of neonatal care (Armentrout, 2007; Cescutti-Butler & Galvin, 2003; Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Gibbins & Chapman, 1996; Heermann et al., 2005; Lee et al., 2009; Miquel-Verges et al., 2009; Orapiriyakul et al., 2007). Inclusion criteria were that participants needed to speak English and agreed to participate in the study. Sample

size was determined based on data saturation and ranged from 8-28 participants in the eleven studies.

Interviews involved a directed conversation for the purpose of obtaining the perceptions of the participants; subsequently allowing the researcher to develop an interpretive understanding (Charmaz, 2006). Four of the eleven studies used in-depth interviewing with an unstructured format to allow the participant to guide the process of data collection (Cescutti-Butler & Galvin, 2003; Fenwick et al., 2001, 2008; Gibbins & Chapman, 1996). Seven of the eleven studies reviewed used a semi-structured interview guide (Armentrout, 2007; Flacking et al., 2006; Flacking et al., 2007; Heermann et al., 2005; Lee et al., 2009; Miquel-Verges et al., 2009; Orapiriyakul et al., 2007).

Four of the eleven reviewed studies used solely audio-taped interviews as the method of data recording (Armentrout, 2007; Cescutti-Butler & Galvin, 2003; Gibbins & Chapman, 1996; Miquel-Verges et al., 2009). The remaining seven studies not only used audio-taped interviews, but also employed participant observations and the development of extensive field notes as complimentary methods of data collection (Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Heermann et al., 2005; Lee et al., 2009; Orapiriyakul et al., 2007). This approach of using more than one method to collect data is referred to as triangulation and adds to the credibility of the research (Hallberg, 2006).

Nine studies used face-to-face in-person interviews (Cescutti-Butler & Galvin, 2003; Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Gibbins & Chapman, 1996; Heermann et al., 2005; Lee et al., 2009; Orapiriyakul et al., 2007) while

two studies used both in-person and telephone interviews (Armentrout, 2007; Miquel-Verges et al., 2009).

Grand tour questions were used by researchers in ten of the eleven studies reviewed (Armentrout, 2007; Cescutti-Butler & Galvin, 2003; Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Gibbins & Chapman, 1996; Heermann et al., 2005; Lee et al., 2009; Orapiriyakul et al., 2007). A grand tour question is a very open, broad question generally used at the beginning of an interview. This general question provides participants with an opportunity to guide and lead the direction of the interview. Researchers then followed up with questions that encouraged elaboration by the participant and the development of a more substantively focused perspective. Armentrout (2007) for example, exemplifies this concept by beginning the process of interviewing with questions about the participant's son or daughter. The phenomenon of interest was to explore the process of coping in parents having to make the decision to withdraw life support from their baby. By encouraging parents to share about their child, the researcher was able to begin to develop a relationship with the participant and to establish rapport. Participants need to feel a level of comfort and trust with the researcher to be able to share personal thoughts and feelings.

### **Reflexivity**

Also important to the process of grounded theory is for researchers to be reflexive and disclose their personal experience with the phenomenon of interest (Charmaz, 2006). This is critical to the process of data collection and interpretation because the researcher enters the world of the participant and through mutual interaction, interprets the data through the researcher's personal lens to then develop concepts, themes and theory

(Charmaz). This disclosure adds to the credibility of both the researcher and the research by providing authenticity regarding the process. Only one of the eleven studies in this review included the personal background of the researcher(s) and the impact on the data collection process. Cescutti-Butler and Galvin (2003) disclosed that the primary researcher was an experienced NICU nurse who came to the research with her own preconceived ideas and observations. The phenomenon of interest was parent perception of NICU nurse competency. Disclosing this information was vital since the experience of the primary researcher impacted the outcomes of the research. No other studies reviewed included discussion of reflexivity within the context of the research (Armentrout, 2007; Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Gibbins & Chapman, 1996; Heermann et al., 2005; Lee et al., 2009; Miquel-Verges et al., 2009; Orapiriyakul et al., 2007).

### **Data Collection and Analysis**

All eleven studies provided detailed description of the data collection and analysis using the constant comparative method during all phases of the research (Armentrout, 2007; Cescutti-Butler & Galvin, 2003; Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Gibbins & Chapman, 1996; Heermann et al., 2005; Lee et al., 2009; Miquel-Verges et al., 2009; Orapiriyakul et al., 2007). Inductive methodology was used with full disclosure of how the researchers progressed from open coding, through selective coding and theoretical coding to the emergence of concepts and categories. Armentrout detailed the process of allowing concepts to emerge from the data through a process of constantly comparing emerging insights to previously collected data. Broad



conceptual categories were developed leading to themes allowing theoretical relationships to be proposed.

Themes that emerged from the data were expressed within the reporting of each of the studies reviewed. Flacking et al. (2006) expressed identifying themes of “life on hold”, “separation”, “conformational and relational interplay” and “care taking” pointing out that the process moved back and forth between different levels of abstraction. Armentrout (2007) described the process of coping for parents withdrawing their child’s life support, themes that emerged included “facing the decision”, “life goes on”, and “lives forever changed” with the core variable identified as “the process of holding a place,” expressing the intense need of the family to carry the baby metaphorically with them throughout the rest of their lives. Identification of a core category was a common component of the research reviewed as it provided structure to the combined meaning of concepts and themes leading to the formation of a theoretical framework (Hallberg, 2006). Researchers exploring the phenomenon of mothering in the NICU identified themes of “struggling to mother” (Fenwick et al., 2001), “learning to be a nursery mother” (Fenwick et al., 2008), “from outsider to engaged parent” (Heermann et al., 2005) and “struggling to get connected” (Orapiriyakul et al., 2007). These themes represent the challenges to mothering when in the NICU. Mothers perceive not only physical distance between themselves and their baby, but identify an emotional distance they struggle to overcome (Fenwick et al., 2001, 2008; Heermann et al.; Orapiriyakul et al.).

## **Developing Theory**

A controversial aspect of grounded theory research is what actually constitutes theory. Before discussing what constitutes theory, we must understand the basic structures underlying theory construction. Charmaz (2006) elaborates on this topic and categorizes the types of theory as being dependent on whether the stance of the researcher is positivist or interpretive. The positivist view supports the ideology of a truth which is discoverable through the process of research. The interpretive approach realizes the existence of multiple realities and values the individuality of perceptions. The positivist and interpretive approaches form the basis for different types of theory. Positivist researchers tend to produce objectivist grounded theory based on the belief that there is an external reality waiting to be discovered. Interpretive researchers produce constructivist grounded theory based on understanding the phenomenon of interest, realizing that data is created and valuing the importance of reflexivity within the process (Charmaz).

Theory or theorizing should rise above the data collected to provide insight into the phenomenon of interest and relationships within the data (Hallberg, 2006). There is an internal logic present, based on interpretive abstraction that provides a greater understanding of the process (Charmaz, 2006; Hallberg). Armentrout (2007) developed a substantive theory that provides a level of abstraction with reference to the process of coping after parents make the decision to withdraw life support from their infant. Thematic concepts include “facing the decision”, “life goes on”, and “lives forever changed”. The core variable was identified as “the process of holding a place”, representing the coping mechanism used by parents moving through their lives by metaphorically taking their child with them. This research moves beyond the data

collected and reaches a level of abstraction from the data to produce understanding of the interpretive process.

Six of the eleven studies explored the impact of the NICU on the role of the mother and were able to reach an abstract level of interpretation to develop theories and frameworks (Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Heermann et al., 2005; Lee et al., 2009). Four of the six studies regarding mothering in the NICU were fundamentally focused on aspects of the experience that differed from my research (Fenwick et al., 2001; Flacking et al., 2006; Flacking et al., 2007; Lee et al.). The concepts included the effect of inhibitive nursing actions on the mother (Fenwick et al., 2001), how breastfeeding impacted the development of the mother role (Flacking et al., 2006; Flacking et al., 2007), and the postnatal impact of the cultural practice of Zuo Yue Zi (Lee et al.).

Two of the studies reviewed are similar to the proposed research (Fenwick et al., 2008; Heermann et al., 2005). Both Fenwick et al. (2008) and Heermann et al. identified the development of the mother role while having a baby in the NICU as a process. Fenwick et al. (2008) identified the core category as “learning to be a mother” which entailed the basic social process of “seeking connection”. A model was developed showing progression through the experience of mothering in the NICU as including phases of “just existing”, “learning and playing the game”, “struggling to mother”, “becoming connected”, and “trying to establish competence”. Mediating factors were identified as the “infant’s wellbeing”, “confidence in self”, and “the relationship between nurse and mother”. The emerging theory was an overview of the work involved with learning to mother in the NICU. Fenwick and colleagues found that mothers’ interaction

with their babies on any level helped establish confidence in the role as mother and assisted in developing the closeness they craved.

Heermann et al. (2005) identified a developmental process that represents the work engaged in by the mother to develop an appropriate role while her child was in the NICU. “Focus”, “Ownership”, “Caregiving” and “Voice” comprise four domains that outline the process of establishing the mother role. A mother begins her experience focused on the technical aspects of the NICU, with the baby in the background. As she becomes more comfortable, and the baby’s condition improves, the mother begins to work to establish ownership. A feeling of belonging helps to establish the confidence needed for a mother to believe in her ability to provide the baby’s care, transitioning the mother to the final domain of advocacy.

The studies by Fenwick et al. (2008) and Heermann et al. (2005) share common themes that provide foundational information regarding the development of the mother role while in the NICU. Mothers begin their experience in the NICU very uncertain and vulnerable regarding their role (Fenwick et al., 2008) and can be very overwhelmed by the physical environment of the NICU with the baby in the background (Heermann et al.).

Both Fenwick et al. (2008) and Heermann et al. (2005) found that the NICU nurse has the potential to either facilitate or inhibit the process of mother role development by supporting access to the baby, or impeding the process through a lack of partnering with the mother. The partnership between the nurse and the mother can lead to successful progress in her mother role development, or can lead to frustration and result in struggling to find the mother role.

As the mother's confidence increases, her feelings of ownership and advocacy of her baby also increase. Confidence builds when the mother becomes familiar with her baby, understands the physiologic condition, and can successfully provide care for her baby. Ownership is when she is able to feel that her baby belongs to her and not to the NICU staff. Finally, advocacy takes place when the mother is confident that she knows her baby and is able to "speak up" for what her baby needs to friends, family and the medical staff (Fenwick et al., 2008; Heermann et al., 2005).

### **Limitations**

A limitation of the research reviewed was the absence of reflexivity and full disclosure of the experience and background of the researcher that may impact the data. This was noted in ten of the eleven studies (Armentrout, 2007; Fenwick et al., 2001, 2008; Flacking et al., 2006; Flacking et al., 2007; Gibbins & Chapman, 1996; Heermann et al., 2005; Lee et al., 2009; Miquel-Verges et al., 2009; Orapiriyakul et al., 2007). Inclusion of a more extensive consideration of reflexivity would have added to the credibility of the data and findings. Interpretation of the data involves the philosophy, beliefs and previous experience of the researcher. This process is critical to acknowledge in the reporting the findings of the research (Charmaz, 2006).

Another limitation is the timing of the interviews in relation to the phenomenon of interest. Interviews ranged from immediately following the event to 12 years from when the phenomenon occurred. Three of the eleven studies omitted this information entirely from the methods section of the publications (Cescutti-Butler & Galvin, 2003; Heermann et al., 2005; Orapiriyakul et al., 2007).

A major limitation identified is the lack of available grounded theory research in the field of Neonatology. As Neonatology evolves, professionals are realizing the

importance of the family and its potential impact on the baby. The NICU is a critical experience for the baby and the family because it lays the foundation for the family and their relationships.

### **Gaps in the Literature**

When reviewing published literature regarding the mother-role in the NICU, it is important to identify gaps in understanding in order to frame future research. The literature provided a basic level of understanding, but additional research is needed to increase our understanding of the internal process of developing the mother role while in the NICU in order to provide the appropriate support. The studies reviewed have not explored the process of becoming a mother in “real time.” In this study, personal journals and in-depth interviews are used to collect data throughout the NICU experience in real time.

Another gap in the literature is in-depth exploration of the mother’s experience of a threatened pregnancy. This is an important issue that influences development of the mother role and affects her ability to cope during the experience of having her baby in the NICU. We need to explore the impact of a threatened pregnancy on a mother’s role development and how it affects her progress as she copes with a baby in the NICU. How does she carry this experience with her as she moves through the period of hospitalization? Is the impact on her role temporary or permanent? Knowing more about how the mother internalizes her pregnancy experience will help the NICU staff to better support her while in the NICU.

During my career in the NICU, I have observed that mothers spend large amounts of time at the bedside of their babies. When it is not her baby’s care time, there are extensive periods of time when a mother simply sits and watches her baby. I believe that

even though it appears that she is simply watching her baby, there is complex and important internal work taking place as the mother evolves her coping style. Researchers need to explore these periods of time to discover the internal mother-work occurring.

An important gap in the literature is what happens when babies experience deterioration in their condition. We need to investigate the impact this has on the mother and her maternal role progression. Does she lose her ability to express her mother role? Or does she leverage her role as mother to navigate the seriousness of her baby's condition? This knowledge will lead to better understanding of how these stages of mother role development integrate and interact to support or impede movement into her role.

Continued qualitative research will provide deeper insight that can enhance the ability of the NICU staff to support mothers while their babies are in the NICU because actions and interventions can be based on knowledge of lived experience. Being aware of critical stages mothers may experience would alert staff to the lack of progression during identified periods of time so that interventions could be used to support the mother's role development.

In the next chapter, the research method used to investigate the process of developing the mother role while in the NICU is discussed. The chapter includes a description of the demographics of the participants, describes methods of data collection, explains the interview process and outlines the data analysis.

Table 2.1 Review of the Literature: Studies Using Grounded Theory in Neonatology

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Armentrout (2007)	grounded theory	n=15 parents: four couples and seven mothers. Eight of the interviews were conducted face to face, and seven were conducted over the telephone.	Aim 1. How do parent describe their experiences with making decisions about life support for their critically ill infants? 2. How does the decision to withdraw life support and the subsequent death of their infant influence the daily lives of parents?	The Core Variable is the Process of Holding a Place: 3 main thematic concepts and their subcategories were discovered 1. Facing the decision (no real choice, time with the baby), 2. Life Goes On (listen to your heart, an abiding loss, not left out) 3. Lives forever changed (new perspective, preparing to meet again).	Parents were able to control the situation by making the decision to remove life support. They sculpted the event and were able to incorporate care-giving activities into the grief process .Maintaining their deceased infant as part of the family unit was of utmost importance to the families in this study. They were forever changed as a result of this situation. Parents were very focused on living a life that would be worthy of their infant's legacy when preparing to meet their infant again in the afterlife.



Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Cescutti-Butler & Galvin (2003)	grounded theory approach	n=8 Inclusion criteria: resident in NICU for more than one week/gestation at birth 28weeks or above/baby ventilated for at least 3 days/discharged home within the past 6 months.	Aim: the exploration of what parents consider competent neonatal nursing practice.	Themes: 1. Process of integration into the NICU by parents feeling they did not belong in the unit and were careful to be mindful of the nursery routine. 2. Parents reported they lacked control of the situation and felt controlled by the staff when interacting with their baby. 3. Parents felt communication was key in their relationship and experience. Most were satisfied with the communication, but some thought it lacking regarding explanations about their infant. Competency was supported by the following: showing genuine concern/made to feel your baby was important/able to make the mother feel more relaxed/showing interest in talking with the parent/bright and friendly manner/having a rapport with them/sympathetic.	This study shows that competence is measured quite differently than basing solely on the technical skills of the staff, but rather includes caring behaviors of the staff. This involves supporting the family in becoming an integral part of the care of their baby while in the NICU. Grounded theory supports the conclusion that when there is a handing over of control to the parents, they feel less like visitors.

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Fenwick et al. (2001)	grounded theory	n=28 women from 2 different hospitals in Australia, however most experienced multiple levels of NICU care. Women were interviewed 2 times (once before discharge and then 8-12 weeks after discharge) Also used interviews from 20 RNs.	Aim: to describe and explain, from the woman's perspective, the experience of mothering in the neonatal nursery. The Aim was to improve the care women and their families receive by providing neonatal nurses with a way of better understanding how to assess women in taking up their role as mothers during such a difficult period.	Critical finding: consequences of the interactions between nurses and mothers: women perceived they gained access to their infant through nurses. The nurse/mother relationship had the potential to significantly impact how women perceived their mothering experience Nurses who were facilitative enhanced opportunities for women to mother nurses could be inhibitive causing the feeling of "struggling to mother".	The grounded theory analysis revealed the inhibitive nursing actions reflected an authoritarian style of clinical practice that was primarily focused on protecting the infant, with nurses directing and teaching the mother. Maintaining the nurse as expert. Developed a model showing the relationship of the subcategories with the major category "struggling to mother".

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Fenwick et al. (2008)	grounded theory	same as above	Aim: to increase knowledge and understanding of how women begin their roles as mothers when their infant is in a NICU.	Basic social problem identified as "learning to be a nursery mother". Women were involved in 4 phases: 1. Just existing 2. Striving to be the baby's mother 3. Trying to establish competence 4. Learning and playing the game. Another significant finding was the important role of the RN in either facilitating or impeding the work of the mother to establish her role.	Compared results to Rubin's theory and had some similarities. Intense emotional and cognitive work revolves around gaining access to their infant. Developed a diagram of the grounded theory "learning to be a nursery mother".

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Flacking et al. (2006)	Inspired by grounded theory	n=25 7 different NICUs in Sweden (98% of all infants are breastfed in Sweden) Interviews took place 3 to 12 months after discharge.	Aim: to explore how mothers of very preterm infants experienced the breastfeeding process emotionally and how this related to the process of becoming a mother, from the time before the infant's birth until discharge from the NICU.	Themes: 1. The loss of the infant, putting life on hold, 2. Separation (a sign of being unimportant as a person and a mother) 3. Critical aspects in the process of becoming more than a physical mother such as initiation of skin to skin and breastfeeding a conformational and relational interplay, care taking (staff negotiation and maternal role attainment) from the infant's critical status to survival.	Compared each of their findings with other theorists. Data revealed that good quality of relationships and social bonds to the baby, staff, father and other mothers helped form a secure bond between mom and baby. Also found mothers in NICUs risk distrustful bonds and accompanied feelings of shame and distrust, ability to cope with stress as some would withdraw. Mothers felt like outsiders initially and didn't know their infant. Nursing staff have a critical role in assisting the development of the mother role.

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Flacking et al. (2007)	same as above	same as above	Aim: to find out how mothers of very preterm infants experience the process of becoming a mother and breastfeeding after the discharge from the NICU.	The process of becoming a mother was represented by changes in the following: emotional state, maternal/infant bond, and the experience of breastfeeding.	Model to represent the pendular changes in emotional state from exhaustion to relief, maternal/infant bond from insecure to secure/breastfeeding from non-reciprocal to reciprocal.

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Gibbins & Chapman (1996)	qualitative grounded theory	n=15 parents 3 days prior to their transfer to an NICU or ICN and then again 5 days post transfer.	Aim: What are parent's perceptions about events surrounding the transfer of their preterm infant within a regional system of perinatal care? To generate a substantive theory about transferring infants within a regional system.	The concept of holding was present in all the parent's experiences from the time their infant was born until homecoming. It was always future directed rather than reflecting back. Four phases are within the concept of holding on 1. Getting sicker 2. Going day by day 3. Getting prepared 4. Stepping toward home. Four major categories are within each phase: 1. being left in the dark, assuming protective surveillance, using coping strategies, and finding a comfort zone.	Parent in the NICU environment are confronted with many stressors, one of which can be the transfer to a different level of NICU care whether at the same facility or different hospital. Parents often feel they have not been communicated with regarding the transfer. Support systems both within the hospital and outside the hospital setting helped parents cope with their stress. Important concepts for staff would be to include parents in the decision making process as much as possible and to have open communication regarding transfer of care.

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Heermann et al. (2005)	qualitative design	n=15 mothers with infants receiving care in a Level III NICU between the ranges of 24-34 weeks gestation.	Aim: focus of this study was the mother's developing relationship with the infant and how their relationship was affected by the nursing staff.	Organizing theme identified as the process of going from "outsider to engaged parent". Results of this study indicated a "process" of maternal development described in four domains named: 1. Focus, 2. Ownership, 3. Caregiving, and 4. Voice. Conceptual model was developed to describe the process.	Mothers develop their role through a process that varies with each individual as to the length of time in each domain. Their progression through each domain prepared them for engaged parenting exemplified by partnering with both their baby and the nursing staff in the NICU.

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Lee et al. (2009)	qualitative grounded theory	n=26 mothers in Taiwan one interview just prior to discharge and observation weekly during visiting time.	Aim: to explore Taiwanese mother's perception of their parenting experiences when their preterm infants were in NICUs by asking 2 questions: 1. How Taiwanese mothers experience the birth of premature infants when practicing Zuo Yue Zi during the postnatal period 2. How do neonatal nurses attempt to meet their needs?	Theoretical model developed from the experience of the Taiwanese mother's experiences during their preterm infants stay in the hospital. Mothers were faced with an unexpected crisis. Cultural postnatal ritual of staying in the house for a one month period of time also complicated the mother's experience. Mothers created alternative channels of contact with their hospitalized infants using emotional connections while the physical interactions were limited.	Mothers felt better being apart from their infant if they felt a sense of "knowing" the infant based on information provided by nursing staff and they would pump their milk and provide personal items of clothing for the baby. They would establish an emotional connection rather than a physical connection during this period of time. The support they received during this period adds to their successful integration of their mother role.



Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Miguel-Verges et al. (2009)	qualitative method	n=22 women Interviews conducted 1 week post consultation and the second interview was 1 week post-delivery usually by phone.	Aim: to investigate parental expectations of a prenatal consultation with a neonatologist for a prenatally diagnosed congenital anomaly, to identify parent's values and unmet needs, and to obtain recommendations for improving physician-parent communication in a prenatal consultation.	Data suggested parents are more concerned with the plan for the pregnancy and perinatal care than the details about the anomaly. Neonatologist provided valuable information about the care of the infant at delivery and the expected NICU course. They liked touring the NICU to see nurses caring for other babies made them feel more comfortable that their baby would be well cared for. Five main themes emerged: preparation/knowledgeable physician/caring providers/allowing hope/time.	The information provided seemed to decrease parent anxiety. They expect care providers to be competent, caring and empathetic. They wanted to know that their baby would be cared for as a person, not an anomaly.

Table 2.1 Continued

Author	Method	Sample	Research Question/Specific Aims	Findings	Conclusion
Orapiriyakul et al. (2007)	grounded theory study	n=15 parents whose preterm infants were 1500 gms or less. Four mother/infant dyad interactions were observed and videotaped for triangulation of data. One interview conducted with each participant and then a second formal interview took place with 5 of the 15 participants for the purpose of member checking.	Aim: to gain more understanding of the actual process of maternal attachment from the mother's perspective and explore the attachment process occurring in the lives of mothers.	The results of the study provide a theoretical model that explains the developmental process of maternal preterm infant attachment in the NICU, characterized by struggling to get connected which was composed of 4 stages: 1. Establishing the connections (occurring during pregnancy), 2. Disrupting of the connections (just after delivery), 3. Resuming to get connected and 4. Becoming connected.	Mothers of pre-terms experience a delay in the attachment process. Conditions that would limit the mother/baby interactions were being physically separated immediately after birth, baby's health condition, emotional grief of the mother and the NICU environment. Struggling to mother was the process the mothers followed to develop their interaction with the baby and interact with others in order to get connected to their baby. The goal of struggling to get connected was to resume the affected maternal attachment to the baby disrupted by the birth.

## CHAPTER THREE

### Research Design and Methods

This chapter will outline the design of the research and the methods used to explore the development of the mother role while in the NICU. The use of purposive sampling, inclusion criteria, and the process of data collection will be discussed in detail.

#### **Design**

A qualitative grounded theory design was used to explore the development of the mother role while in the NICU. This method allowed for an in-depth exploration of the process of mother-role development during the actual experience of having an infant in the NICU. Qualitative methodology was used to allow me as the researcher not only to enter the world of the participant but also to use my personal experience to interpret the data. Grounded theory was applied to expand the body of knowledge surrounding the process of mother role development in this population. A theoretical model, the ultimate objective, outlining the stages of mother role development will add to the current body of literature and allow for continued exploration by researchers and healthcare professionals to support and assist mothers facing the challenges of developing their role while in the NICU.

#### **Methods**

##### ***Sampling***

Purposive sampling was used in the selection of participants. English speaking first-time mothers at least 21 years of age with good verbal skills who were interested in participating in this research and had an infant requiring at least four weeks of hospitalization in the NICU were considered viable candidates for this study. Mothers

identified as potential participants received institutional review board (IRB) approved information about the study. Mothers were able to sign the consent, or contact the principal investigator (PI) after considering participation. A copy of the signed consent was given to the mother for her records. The sample included five pregnant women. Four of the women were Caucasian and one was African American (see Table 3.1). Ages ranged from 22-29 years of age. Four were Gravida 1 Para 1 (G1P1) mothers, meaning they had been pregnant one time and had one live birth. One mother was a Gravida 2 Para 1 (G2P1) meaning she had been pregnant twice with her first pregnancy ending in miscarriage and had one live birth. Infant gestational ages ranged from 24-31.4 weeks with weights ranging from 780-1370grams at birth. All were English speaking.

### ***Data Collection***

Institutional Review Board (IRB) approval from the Biomedical Behavioral IRB at the University of Kentucky was obtained prior to beginning the study. Data collection was undertaken from June 2012- April 2013. Data collection methods involved personal journals, semi-structured individual participant interviews, researcher observation and memo-writing. Participants received a journal with written instructions at the start of the study regarding the criteria for journal entries. Participants were encouraged to make a journal entry at the time they experienced a positive or a negative mother-role event as self-defined. These event-driven journal entries were copied prior to each in-person interview (see Appendix). The personal journals provided the framework and guidance for subsequent interviews which, in turn, facilitated a deeper understanding of the data. In-depth interviews began with a grand tour question, “Tell me about your experience of becoming a mother”, to provide exploration into this process of mother role development.

The interviews used a semi-structured format that included questions on the participant's perceptions of their mother-role prior to pregnancy, during pregnancy, at the time of delivery, and during their NICU experience; emphasis was also placed on exploring the mother's experience during times of physiologic changes in the infant. Interviews with participants were audio-taped to assure accuracy of data collection. Observation and memo-writing were used to document body language and other nonverbal observations during the interview to supplement the data collection. Member-checking during the interviews verified data previously collected to improve accuracy as determined by the participant and to optimize interpretation of the data.

The constant comparative method was used throughout the study to incorporate new data with previously collected data to review and study emerging categories and concepts. This method of data analysis is a creative process used in qualitative research for the purpose of theory generation. I preferred to not use a computer program to synthesize the data, but rather to review over both the previously collected data with the new data and to develop my own categories and concepts using index cards with quotations to group common themes. This was the foundation for the development of the model with five distinct stages for this dissertation work (Boeije, 2002).

A large amount of data was generated from the mother's journals. Daily entries were not required for the study, but rather mothers were encouraged to keep a record of significant events that occurred during their NICU experience. Four of the five participant mothers provided daily entries that included the progress of their baby's health condition, weight, personality, and their feelings along their NICU journey. The journals were a treasured keepsake and seemed to provide the mothers with a therapeutic

outlet for their feelings and experiences while they sat at their baby's bedside. The personal journals shared data in real time instead of reflection after the event had occurred. Mothers expressed their delight of being able to share their journal with their child, "*once he is old enough to understand!*"

The length of time for each participant interview ranged from 20 -180 minutes. It is important to note that the participant whose interview lasted only 20 minutes provided very in-depth personal journal entries that were very open and expressive of her experience. This made using multiple sources of data quite valuable to this research.

The process of interviewing mothers proved to be quite challenging due to multiple factors. Mothers were eager to schedule a time to meet for the interview, but conflicts would arise because of their visiting schedule. It also seemed difficult for mothers to be away from the baby's bedside. As a result, interviews were scheduled for a time when the unit was closed due to sterile procedures. This seemed to provide some relief to the mothers as it gave them a place to be that was close to their baby.

Interviews were conducted in a conference room that was located in the NICU. There was close attention to detail regarding room temperature, comfortable chairs, and assurance that the mother would be alerted if she was needed at the bedside of her infant.

Along with data from personal journals, audio-taped participant interviews and researcher's notes, the mother's name, age, ethnicity, obstetric history, gestational age of the infant at birth, weight and age of the infant were collected. A coding system was developed to de-identify the data. The coded data and the original data were kept locked in separate locations in the NICU Patient Care Manager's office.

## ***Data Analysis***

The constant comparative method was used for exploration into the development of the mother role while in the NICU. This process of analysis is not static and linear, but rather fluid; data is constantly reviewed while incorporating new data into the process and re-evaluating the interpretation and meaning. The data obtained from journals, participant interviews and my field notes were transcribed into the computer. “Express Scribe” (n.d.) was used to transcribe the interviews to control the speed of the recording and to enhance accuracy. Transcription took approximately three hours to type a one-hour interview. At the same time, this laborious process allowed the opportunity to “re-enter” the interview, allowing for continued re-processing of the data in the detection of nuances of the exchange that might not have been revealed had someone else undertaken the transcription.

Initially, the computer program “In-Vivo” was used to analyze the data. The program clearly added an element of objectivity and facilitated handling a large amount of data, however, seemed to be sterile by not using the researchers’ experience and background to filter and interpret the data. It is for this reason that in the end, I chose not to use the In-Vivo program.

Data was coded to begin the process of conceptualizing (Charmaz, 2006). Open coding involved staying close to the data and choosing key words to represent each line of data for example: work, excitement, scared, blood pressure, and weight gain. Focused coding was the next stage of the analysis and involved a selective process of synthesizing larger segments of data for example: pregnancy, health, anxiety and delivery. Once the codes were established, the material was then reduced into categories such as emotions,

support, condition of the baby, and trust. Axial coding was used to create relationships around a central category, or 'axis' by grouping and assimilating the categories and their subcategories for example looking at the issues surrounding "trust" which could be of the process of delivery, the nursing staff, and of other families. Theoretical coding was used to create the meaning and understanding of the data by conceptual interpretation of the codes. It uses the selected and focused codes to lay the foundation for the theoretical framework. Themes emerged from the analytic interpretation of codes and categories leading to a deeper level of understanding and advanced the construction of the theoretical model such as the concepts of a threat, surreal experience, support, and mother role. It was at this point that a common developmental process of the mother role was shared among the participants in the study and supported the stages of the theoretical model.

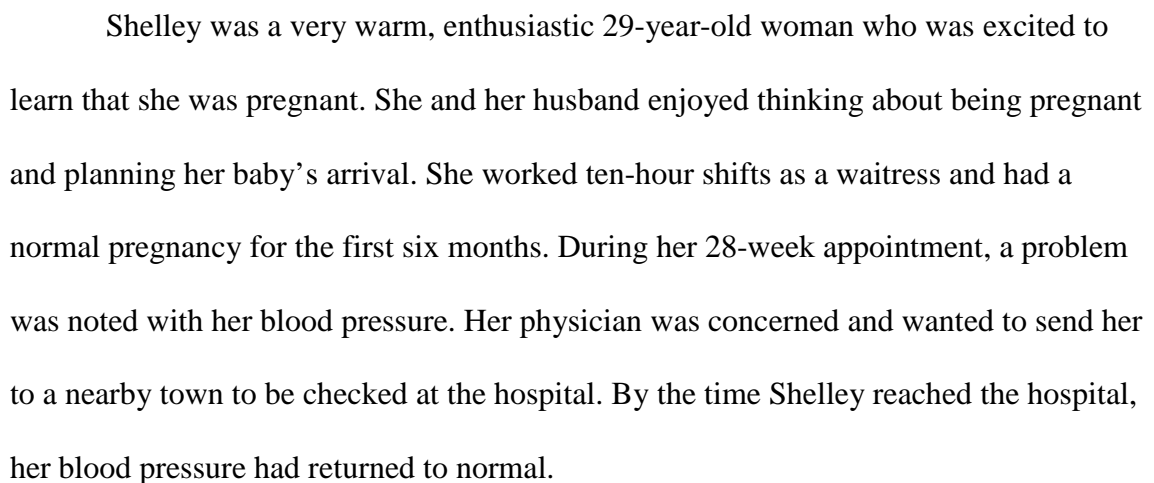
In the next five chapters, stories of the mothers who participated in the study and their personal experiences of developing their mother role while their baby was in the NICU will be described. In the following chapters, each of the five participants is identified by a fictitious name and summarized by an image generated from Word Cloud (Feinberg, 2013).



Table 3.1 Personal and Sociodemographic Characteristics of Study Participants ( $N=5$ )

Characteristics	<i>n</i>
Marital Status	
Separated/Divorced	0
Married	2
Significant Other	3
First Pregnancy	
Yes	4
No	1
Living Children	
1	5
2	0
Ethnicity	
White	4
African American	1
Age of Mother	
20-25	3
26-29	2
Gestational Age of Baby	
24-26 weeks	3
27-29 weeks	1
30-31.4 weeks	1
Birth Weight of Baby	
780-1000 grams	4
1000-1370 grams	1

## Shelley



For the next few weeks the obstetrician monitored Shelley's pregnancy closely. She had experienced a dramatic increase in weight along with her blood pressure issues, and her physician explained she could be developing preeclampsia. When Shelley was 31 weeks gestation she realized something was quite wrong, "...I woke up with a pain in my upper back I cannot quite describe, however, at the time I remember thinking I must be losing this baby." Her husband rushed her to the hospital. The ride seemed to take forever.

The hospital staff acted quickly, preparing Shelley for a caesarian section. Before she knew it, she was being told to count to ten as the anesthesia took effect. Shelley wrote about when she woke up:

*The next thing I can remember is my mother and my husband telling me to wake up and feeling very sleepy. I was sent to recovery. For two days I could only see a picture of my son who was 3 pounds, 0 .03 ounces and 16 inches long. I would find myself touching my stomach looking for his kicks that where no longer there. It's a very strange feeling to know you have just given birth but still feel like you are pregnant.*

After spending two days in recovery, Shelley began to improve enough that the staff were able to move her to the mother/baby floor of the hospital. She was excited to be able to see her baby for the first time. Shelley refused a wheelchair because she felt fine and was so focused on her baby:

*I remember going in for the first time to see my baby boy.....I have never seen nor imagined something that small and fragile. He had a feeding tube in his nose because he didn't know how to eat yet. And a little bit of oxygen and an IV and things in his navel. I just remember being scared still that he might not make it. The nurses in the NICU reassured me that he was tiny but mighty. The incubator he was in had a cute little blanket on top and his name all decorated for display. Even though I was seeing him for the first time it felt like we had already met each other. I also noticed his giant feet which I can be certain are the exact replica of my own. He was so beautiful. I don't really know how I expected his birth would be, but I never prepared for the idea that I wouldn't be able to touch him, hold him, feed him, or even change him. All I could do now was stare at him through his little box.*

Shelley spent many hours sitting and watching her baby. She closely connected with the nursing staff and learned the routine of the NICU. Shelley became familiar with the medical language the staff used when talking about her baby. She learned that he needed the oxygen for his breathing and the incubator to keep warm. Her baby improved and progressed rapidly and the nursing staff would brag about him, which made Shelley so proud. She began to breathe easier knowing that her baby was going to be fine.

Shelley met with the lactation nurse so that she could provide breast milk for her baby. She liked that this was something that only she could do as his mother. She was very committed to pumping every 3-4 hours and transporting her breast milk to the hospital so that it could be stored in the freezers. Shelley made sure that her baby always had a supply of her milk.

She lived to touch him, take his temperature, change his diaper and feed her baby through a tube. These activities helped her to feel like a mother and were considered celebrated milestones. Some infants when they are born do not tolerate touch or even talking at their bedside. The most a mother may be able to do with her infant is to lay her hand on the baby without movement. As the baby's condition becomes more stable, the mother is able to participate in caregiving activities. The mother will cherish changing the first diaper, taking the first temperature, or the first time her baby grasps her finger.

When Shelley's baby was stable enough, it was time to begin feeding him with a bottle. Shelley was very excited and nervous to see how he would tolerate sucking on his first bottle:

*His first couple of attempts at a bottle (when I didn't know if I could nurse) were a little scary... he didn't know how to swallow yet and it scared me to hear his monitor beep. On the third or maybe fourth try at the bottle he started figuring it*

*out. Lactation came and asked me how I felt about nursing and I was more than ready (I had been pumping up until that point).*

Shelley became used to the routine of caring for her baby while he was in the NICU. She desperately wanted to take him home, but realized that the best place for him was to stay in the unit and grow. Shelley became more confident in her mothering skills and waited to perform these motherly things for her baby during his care times. One time, the nurse was unaware that Shelley was on her way to the hospital:

*I wish that his nurses would realize that I as his mother do not nor have I ever deliberately tried to make their job more difficult. There is nothing that crushed my soul more than going in to feed him or change him to find that his nurse had already done all of the work. It feels wrong, like wait a minute that is my job, my responsibility as his mother to protect him to feed him. I should be doing this.*

Shelley became very knowledgeable about her baby's progress. Her journal contained entries showing an understanding of his clinical condition and progress:

*Today at day 23 he is eating between 40mls and 50, he is allowed as much as he wants...I got to sit with him while the doctors did their rounds. The incubator is on 81.4 today they are trying to wean him down and get him into a big boy bed.*

Shelley wanted to spend every moment with her baby. At times she felt frustrated by having to wait until the next care time to get to touch him and care for him:

*I nursed him at 11 and then at 12:00 he was out like a light sleeping so I went down to the café to get some lunch. I'm supposed to go back at 1:30 pm but I can't wait. I think I will just go stare at him until it's time to get him back up to eat again....*

As time passed, Shelley became calmer in her demeanor, smiling constantly and staring at her baby. She seemed to glow as she talked about preparing for home:

*I do however know that my baby is different, he was a preemie. My baby is too little to do what a full term baby does....but he is doing it. They say he shouldn't be eating like that, but he wants it. And my favorite is when the doctor says he thinks he's big... he doesn't know he is little. I am so proud to be his mom. I hear people say how I better enjoy this chance to rest while he is in the NICU nursery because when he gets home I will never sleep....but I don't need sleep. I need him. I feel like anyone who has a baby before its time must feel the same as we do. I am*

*not totally prepared as far as material things go but we are getting there. I have to get a new car seat because he needs a 4pound+ and the one we got was 5+, but I don't mind I am just so ready to take him home and be the only voice he wants to hear.*

Shelley and her husband were thrilled to hear they would be taking their baby home. Shelley's baby had improved so rapidly and continued to gain weight and eat well that he was ready for discharge before anyone predicted! They still had last minute details to finish up before the big day, so she would stop in to feed her baby and then have to leave to continue preparing. When I would see Shelley and her husband they were literally running up the stairs to make the feeding time and once at the bedside it was as if time stood still. They were full of smiles and would speak to their baby softly, watching every expression. Shelley had a very calm confidence and was constantly smiling. Shelley and her husband took their baby home later that day amid good-byes and good luck wishes from the staff.

## CHAPTER FIVE

Bailey



Bailey was warm, energetic 25-year-old who was always smiling. She worked as a nursing care tech (NCT) and was in college studying to become a speech therapist. Bailey and her significant other came from very large, close families. Bailey lived with her sister, and the father of the baby lived with his family. They had a very good relationship and were committed to each other. Bailey was surprised to discover she was pregnant, but she was happy. At 12 weeks gestation, Bailey began to experience problems with her cervix. She had to be monitored closely by her obstetrician and was

placed on bed rest when her cervical funneling worsened. It was very difficult for her to balance working and the need for bed rest:

*I was working at times...like oh you gotta work...and then it's like no...go to work... for about a month or two of that ...every other go to the doctor...watching me weekly and the funneling would be ok...there would be a little funneling...but then after work for a week or two...I would have bleeding...and they wouldn't know what was causing the bleeding...or was I straining myself...and then back on bed rest, so once I was back on bed rest they seen that I still was funneling like majorly.*

Bailey experienced a lot of stress because of the uncertainty of her pregnancy and her lack of ability to control what was happening:

*I was on bed rest...I was to do nothing but to get up to use the bathroom...You're like what am I doing wrong?...every time it would be...you are doing really good...stay on strict bed rest...don't get up to do anything but use the bathroom...then you would come back the next time and it wouldn't be as good...but you didn't do anything different.*

Bailey began to feel the effects of an uncertain pregnancy, inability to work, and financial demands:

*...so then I reached the depressed stage...because you are just in the house by yourself...and with me...we live in separate houses...me and dad...and when I got pregnant and on bed rest...he had to take on my payment on my house and his house...so I would never see him.*

At 24 weeks gestation, Bailey realized the baby was coming and she needed to get to the hospital. It all happened so quickly, the medical staff rushed her to labor hall and before she knew it, the baby was out:

*...so, it was just like unreal...it was really so surreal to me...you still didn't... I'm like...feeling pregnant because all the complications...so you never got the baby shower...none of that...you know nothing big...my stomach got big...but not to the OMG...you are really big and pregnant...never got to that stage...yet. So I just was 6 months and I was just starting to get round...yea...cause that's the symbolic part of it...that everyone can see...so you were just getting to that stage...and getting round and getting bigger...and you miss all that...you just don't get that...when you have a preemie.*



She couldn't believe it, the delivery was so fast. Bailey still felt pregnant, but she knew that she wasn't. At the delivery she didn't get to see her baby, or hear him cry. She and the baby's father went to the NICU to see her baby for the first time:

*It felt weird at first...you are like...wow I am a parent...but you still don't feel it...because you didn't get to hold him and it was still weeks before you get to kiss and hug him. When we first came up there...we were like...we sat down first for 3 hours and said...We're parents...like he's here....we sat in awe for a while...so we came upstairs...he was just an ity bity thing...I feel like I am going to break him if I touch him...and we listened to everything the doctors and nurses had to say and all the care they had to do...and when to touch him and not to stimulate him too much and you were like this is so overwhelming and you still want to be like so hands on...and you can't ....they're so small...and that's really hard...but we did get to let him hold our finger...and he had a good grip...so that was a good feeling... 'cause that was the closest contact you could get....no kissing...no taking pictures...it was so dark in there...it was just unreal.*

Bailey felt a strong need to be with her baby, even if it was just to sit at his bedside and stare at him. She felt like an assistant to the nursing staff because they knew so much more than she did about what her baby needed. Bailey wanted to know what it felt like to be woken up at 2 am to feed her baby at home, instead she felt disconnected because of the regimented schedule of pumping every three hours and bringing it to the hospital, handing it to the nursing staff.

The NICU was such a strange scary place to Bailey; she was intimidated and asked many questions. She would ask the nursing staff for permission to be able to begin his care, being overwhelmed by all the rules. She found that she spent great amount of time waiting between care times, for the unit to open, for the next set of labs, for her baby to open his eyes. While she was waiting, she was also watching. Bailey studied every inch of her baby recognizing family traits such as her baby's toes resembling hers. This delighted her because it assured her that this was her baby. She was amazed by his strength and how much he wiggled and moved around, being so tiny. Bailey captured

these moments in pictures and video and would watch them when she was pumping to stimulate her milk production. She became quite panicked when her supply of breast milk seemed to diminish. It was the one thing that she could provide for her baby, and the thought of not being able to produce what he needed was extremely stressful. Bailey met with the lactation staff and worked diligently to maintain her supply for her baby.

As her baby's condition became more stable and he continued to grow, the days became more predictable for Bailey. She would kangaroo with her baby allowing her the closeness she craved, "*he snuggles (during kangaroo care)...so I love that he loves that time...*" Bailey felt more confident in providing her baby's care. When the nursing staff would ask if she needed help, she would reply, "*...I got this!!!*" Bailey never thought this time would come, that she would feel so comfortable and happy. It had been two months since the birth of her baby and she was amazed at how much they had all grown:

*It's unreal...it's kinda picked up pace...I really wasn't thinking it would be this fast...they were going to take him and put him on cpap....and we thought we would have to go through all the stages of cpap...and then like the next day...after we hit 4...they said we could try him off...dad was really adamant...can we really take it off now???...and he was so funny...we were like...is this the milestone we are not going to get over...we kept looking at him and looking at the clock...back and forth...and watch everything...and oh my goodness...he was actually doing better....he was so dingy (dropping his heart rate)...and he brings his self-back so fast...this is great!!!!*

Bailey felt like the "go to person" because she was constantly at the bedside and knew what her baby liked and didn't like. The nursing staff knew her well and let her do everything for her baby, even start his care times without asking permission. Bailey had a big family and loved to show off her baby. She would show them what he could do and explain how much he was feeding, and how much he weighed. Bailey was very proud of her baby.

Bailey's baby continued to grow and get stronger. She loved being able to breastfeed her baby and was excited that she was able to have so much contact. She really felt like she was becoming the expert about her baby and stayed focused on the positive. Bailey was smiling constantly, and laughing. She firmly believed that by being with her baby every day so he could hear her voice gave her baby the strength to grow and get well.

Bailey's life outside the hospital had been on hold since her baby was born. Bailey spent every moment she could at the hospital. She realized now that her baby was doing so well, that soon it would be time to take her baby home. Bailey had to begin looking for a new place that would be suitable for her family:

*... we are just trying to get everything ready and packed up to move...sweating bullets now....we are rushing...everything is going to be new...for us...it's going to be great to bring him to a new home and new for us as well...*

Bailey's excitement grew as she realized that her moment was coming:

*...my big day!!!!...so now our big moment is really taking him home...getting to show him off to the world...and he is so much bigger...and it was so hard before having to visit with them one at a time...and they would get jealous...and we just wanted to be with him by ourselves...and we would wait for it to be 9 pm so they would have to leave...and now we will be at home. Now I will be like....come on...and you can see the baby.*

Bailey was very excited but also worried about leaving the experienced staff in the NICU. She realized that she would be responsible for her baby when she took him home and worried that she would miss recognizing signs that required a doctor's attention, *"...to say this looks different...you won't have that at home...I will be calling the hospital and getting on people's nerves....just to ask questions..."*

Bailey made careful plans for when she took her baby home. She mimicked the visitation policy of the NICU and was going to keep all visitors away until the spring.

Bailey had a lot of family members that worked in the school system, and she felt their exposure to contagions would be high. The NICU staff tried to explain what could be done to prevent the spread of infection to allow some of her family to visit, but Bailey wasn't interested in taking any chances. She was quite content with her plan and felt it was the safest was for her baby.

Just when discussions about discharge were beginning, Bailey's baby began to experience desaturations in his oxygenation. This was unusual for her baby and concerned the medical staff. Her baby began to require being "bagged" (providing breaths using a resuscitation bag) with a higher oxygen concentration to increase his oxygen level and heart rate. The nurse practitioner caring for Bailey's baby called her to explain the change in her baby's condition. Bailey came running into the unit and had an expression of sheer terror:

*(heavy sigh)...it was unreal...we didn't know what was going on...he just kept desatin' and desatin'....and everything went just downhill....and it was a shock for everybody...but they came up to do the chest x-ray...he had desatted so much....and then we left...and then came back to check on him...and then with the depression...going downward....and then the practitioner called and said that he was dessating...and he never did that stuff...it definitely was heartbreaking...we went for days and just didn't know.*

The medical staff ordered lab tests to see what was causing the change in Bailey's baby. He had to be placed on the ventilator to improve his respiratory stability. Bailey was told they suspected he had contracted an infection from her breast milk:

*...and they were like 100% sure it was from me....but I hadn't felt sick at all....and everyone I talked to said the same thing...everybody was pointing the finger at you....felt pretty crappy....cause I felt like I had gotten him sick....cause he had pneumonia...and he was completely going purple...it was unreal...me and dad were really hurt...so then we were like how did he get it...and how did we get it...it was unreal, but then it came back that I didn't have any signs in my breast milk.*

Bailey felt betrayed by the very people she had grown to trust with her precious baby. She distanced herself from the hospital because she didn't want to make her baby worse. She carried around the guilt that somehow she had made her baby sick. She busied herself with packing her things to move but felt helpless at the same time. Bailey felt that all the progress they made was gone:

*I felt like it was snatched away...because then they put him on the vent...and we couldn't get him out...I got him out twice when he was on the vent...with many days between...so it was just like...we were back at stage one...kinda how I feel. I had been able to do all his care...but then I couldn't do his care....and then when we would get to...they would hover and you felt like you were going to do something wrong...it felt like completely starting all over from day one...that was very depressing...it was pretty bad, cause then you were like....then you don't know if you are going to get to take him home or not...and you could just see that he had no strength....even after growing so much.*

Bailey's world was once again filled with uncertainty. She was back in a place that she felt she couldn't do anything to help her baby and worried about his survival. All she could do when she visited was sit and stare at her baby and pray:

*You can tell he didn't have too much fight left...he was just so tired...that was very hard to watch him...and not be able to even comfort him and hold him....so....and then it took a while to see him even active...so that was the scary part...and I know the patient beside us had just passed away...kinda made you feel that he was going to be next....his neighbor had been doing fine and then gone....and you just don't know...even in the beginning you didn't know...but you had the steps...to follow...but with this, we just didn't know...it depended on what happened...to see what would happen next.*

Bailey listened intently to the staff and had to learn new terms and equipment being used to keep her baby alive. She had to study what medications he was on and what his labs were showing. Her baby's condition began to stabilize somewhat, but Bailey couldn't relax. The providers spoke with her about her baby having a potential permanent loss of hearing. Bailey felt her world was spinning out of control, but knew that she needed to provide her baby with whatever he needed:

*We were asking everyone...about everything...you couldn't help but look ahead...what we were going to need to do next to help him prepare for that next stage...it was really hard...it was an eye opener. Cause entering a whole new world and absolutely clueless about everything...and had no guidance or anything.*

The hearing test was repeated and showed mild hearing loss. Bailey was elated that they finally had some good news. Once the infection resolved, her baby was weaned off the ventilator and then off all oxygen shortly after. Bailey remained cautious in her optimism, realizing that even though he had made it through so many challenges, her baby was still fragile:

*I'm more scared especially with his breathing...just because he's not going to be on no type of monitor...nothing to look at to see if his heart rate is too high or too low...when he got sick...it happened so fast...I'm scared...oh gosh we are going to be sleeping and he's purple...and that's the biggest fear because it just happened so fast...the day we found out he was sick...dad was holding him...he looked at him and said "his lips are purple"...and the nurse had to bag him...and we aren't going to have this technique at home and not have a nurse there...so that is so scary.*

Her baby continued to recover and soon was ready to go home. Bailey's confidence had grown, but she was still apprehensive about leaving the supportive environment of the NICU. She knew that she would be responsible for the wellbeing of her baby at home, which both thrilled and scared her. Bailey came to the unit on the day of discharge and prepared her baby to go home. She was smiling with a slight look of apprehension in her eyes as she walked out of the NICU. The nursing staff lined the hallway and wished them well. Bailey turned around one last time and waved good-bye with a big warm smile.

## CHAPTER SIX

Nicole



Nicole was a 29-year-old, who was very straight forward and expressive with her emotions. She had a fair complexion with strawberry blonde hair and pretty blue eyes. At the time of discovering she was pregnant, she worked full time with mentally challenged adults. Nicole was married and had a prior pregnancy that ended in miscarriage. Nicole had a very determined personality and knew from early on that being pregnant was not for her, *“I hated being pregnant...I mean I love the outcome...wouldn’t change it for anything else...but as far as being pregnant...no...hard emotionally, physically, mentally, I mean yeah, it was hard.”*

Even though she did not feel well during the first part of her pregnancy, she was able to work every day. Nicole was diagnosed with gestational diabetes. She had an appointment for diabetic teaching to learn how to administer insulin. The plan was that she would remain in the hospital for 3-5 days to be monitored. Once Nicole was admitted to the hospital, she was connected to a fetal monitor to track the baby's condition. The monitor indicated that her baby was experiencing heart rate drops. Nicole was given steroids to help develop the baby's lungs in the event an early delivery was warranted. She was placed on bed rest and didn't understand exactly what was happening with her baby. Nicole wanted to know why her baby's heart rate kept dropping, but the physicians explained that they just were not sure of the reason. The next day, Nicole began feeling pelvic pressure and reported this to the nurse and then to her physician later in the day. Nicole experienced contractions, at times requiring frequent monitoring. She worried about her baby having a heart defect when a physician explained that some possible abnormalities were noted during an echocardiogram. Later that same night the contractions returned and Nicole notified the medical team. The physician checked her cervix, determining it was at 6.5 centimeters dilation. After unsuccessful attempts to stop her labor; Nicole delivered her baby at 25.5 weeks gestation. She shared feelings of guilt about the premature delivery:

*(Blame) I still do... (Crying)...I don't know...I mean....maybe if I would have said something earlier it wouldn't have happened... (crying)...everybody's like it's not your fault...but you know, I mean...(crying)...I don't know...it is my fault...because I didn't say anything....if I would have said something earlier...maybe it wouldn't have happened...maybe I would still be carrying him around...I don't know...*

Her baby required a ventilator to assist with breathing and phototherapy for jaundice. The nursing staff helped Nicole change her baby's diaper for the first time and to use soft gauze with water to wash his face. She quickly determined that her baby had a



very strong minded personality, even though he was so small, “... like I said...he's got his temperament...oh my goodness...like today I gave him a kiss...and he didn't want one...and he let me have it!”

Nicole delighted in watching her baby and would point out many family traits that he shared:

*His hair was darker and now it's got tints of red like mine...we have red heads in our family...his dad's hair is dark and curly. I have a cousin with fire engine red hair...her mother hated it...I don't mind...and he has the temperament of a red head...and the pale skin....like mine. His dad is dark skinned...gets a real good tan...I turn red and blister....we don't do 15 suntan lotion we do 90...*

The medical team determined that Nicole's baby was ready to begin breast milk tube feedings. Nicole became very frustrated because she knew that providing breast milk was the one thing that only she could do for her baby to help him grow. The problem was that her milk hadn't come in yet. Nicole felt inadequate and signed consent for her baby to receive donor milk until her own milk supply increased. She remained determined to be able to provide milk for her baby and pumped every 3-4 hours through the day and night. Nicole's hard work paid off when she was able to provide her baby with her own breast milk.

Nicole quickly learned about her baby's medical condition and the terms used by the medical staff. She tracked his progress with great detail in her journal. She kept record of his weight gain, feeding amount, and current medications as well as what he liked and didn't like during the day. Nicole would set goals along the way:

*To have his rate down on his oxygen...he's been fluctuating...between 27 and 30...but then he had to do some work...and he got lazy and they had to go up...because he wanted to desat and stuff...but maybe we will be down...and then we started last night...started lowering the temp on his bed...hopefully in the next couple of weeks we can be holding our temperature...it's a goal...and if he doesn't reach it it's ok...I understand that if it doesn't happen...it's not a setback...you just have to go one day at a time. My ring that I wear...is my moms and it goes all the*

*way up on his arm....and we took pictures...and are keeping a book for him...this is the first preemie in my family...and maybe it can help them to know what to expect.*

Nicole established a routine for her days which gave her comfort. She would come to the unit around 10am every day and go straight to her baby's bedside. She would stay at the hospital for most of the day, taking a brief break late in the afternoon when the unit closed for shift change. She quickly became the expert regarding her baby and felt very free to share this with the physicians when she felt something was different with her baby:

*...she (the doctor) come in and I told her...he doesn't look right...and she said...well, he doesn't look out of the ordinary to me...and I was like...I know him...I am here every day...and she ordered his blood work and his blood was low...he didn't have enough in his system...and he had to get a second transfusion...*

Nicole developed close relationships with the nursing staff, especially her baby's primary nurse. From the beginning, the staff supported and encouraged her to care for her baby. Nicole was a quick study and learned everything about her baby. She was very open with the staff and asked that they would call her if her baby was crying inconsolably. When Nicole found out that her baby was crying one night and she wasn't called, she was not comfortable with that particular nurse caring for her baby. She didn't like to complain, but felt that she was looking out for the best interest of her baby:

*It's just like you know I've got one particular nurse that I don't care for...and I made it be known...and she's no longer taking care of him...well she doesn't need to be taking care of him. I've not had any problems with any other nurses...she was just...might have been having an off night...don't know what her deal is...but...I am his mom...and it pissed me off....so she's not one of his primaries anymore.*

Even though Nicole missed her family terribly, she stayed at the hospital with her baby. She had not left since she was admitted prior to her delivery. She watched over her baby very carefully and only planned to go to her doctor's appointment back home if her

primary nurse was caring for her baby on that particular day. This seemed to be a way that Nicole could control the situation, by ensuring preferred nurses were caring for her baby. She insisted on care that was attentive to both her and her baby. She couldn't imagine leaving him and something happening. She had very strong relationships with her family that now included her baby.

Nicole was very aware of what was going on in the nursery around her baby. She developed a relationship with two families that had babies in the NICU and were also staying at the Ronald McDonald House where she was accommodated. She was very torn, feeling resentful of those families getting to take their babies home. However, she was pleased that her baby was doing well and felt that she should be very thankful. She felt guilty for having these thoughts of resentment, since some families had to deal with the loss of their baby. This made her very emotional when she would think about these families experiencing loss, and worried that something would happen to her baby:

*I look at their situation....and in the same instance it's depressing and being happy all at the same time...they've gotten news that they don't even know if their baby is going to live through the week....and the mom posted pics and it doesn't look like the same baby...and then I am just worried about my baby coming off the bubble and coming home...and they are worried about if they are going to see their baby the next day... (Crying)...*

Nicole witnessed situations she felt were unjust, such as parents who seemed to never visit their baby in the NICU, choosing to stay at the Ronald McDonald House all day. She felt bad for those babies because their families didn't visit. This created a feeling of sadness because she felt the babies weren't getting what they needed.

Nicole would reference how things would be once she took her baby home. She felt like in the NICU, her baby was "the boss" to a point. She explained that everything was done according to what he needed, which was fine. But she pointed out that once

they were home, it's going to be her deciding what her baby needed and what would be best. She pointed out that they both had strong personalities and that she would be the ultimate boss!

During her time in the unit, Nicole would plan for when her baby would come home. She was very excited to have her baby at home with all of her family. She thought about how she and her husband would set up their routine, incorporating the baby into their life. Nicole planned on working part time with a schedule that would be opposite of her husband so that one of them was always at home with the baby. She planned to have her sister help to watch the baby, if needed. Nicole decided it was very important for her baby to be at home with family. She enjoyed talking about when they would all be home together, even with their dog that was a very important part of the family.

Nicole's baby reached the goals for discharge to home by weaning off oxygen, taking all feedings by bottle, and having consistent weight gain. Nicole was so proud of her baby and so excited to finally be able to have her family together. Her husband brought the items needed to take their baby home. Nicole and her husband took their baby home later that day to celebrate with close family in their home.

## CHAPTER SEVEN

Jaime



Jaime was a very spirited 23-year-old with deep reddish hair and light freckles. She was living with her significant other and his family. Her pregnancy was not planned, but she was excited to learn she was having a baby. Jaime worked odd jobs with her significant other's family and was able to maintain her usual routine. She experienced some nausea with her pregnancy, which was otherwise unremarkable until she was 26 weeks gestation:

*...and I didn't even know that I was having contractions when I had her. I was having really bad pain and bleeding and I didn't think anything of it because I read on the internet that things can happen and you can bleed a little bit...but then the pain was very sharp and I cried.*

Jaime did not understand what was happening, but hoped that it would stop.

When she realized it wasn't going to stop, she went to the nearest hospital:

*It was early in the morning and I just waited and had trouble sleeping...kept waking up, so when I went to the hospital they said my WBC count was high and then they said I needed to rush and get to the county hospital...so I got to the other hospital and they brought me upstairs to the room and the next thing I was 8 cm dilated and said that it was normal that my WBC count was high because of being pregnant.*

The medical team quickly realized that the labor couldn't be stopped and began to prepare Jaime for delivery of her 27 week gestation baby, *"It was real quick...they found out I was 8 cm dilated and they broke my water and push...4 pushes and done. It was like 5 minutes..."*

Jaime was able to see her baby just before she was transported to the Regional Referral Center and remembers how very tiny she was, *"When I saw her I was scared.....I had not ever seen anything that small..."*

Jaime had to remain in the local hospital until the next day when they were able to release her:

*... (waiting) just until the morning...and then they discharged me 'cause I kept bugging them....needed to go outside to smoke...and they let me...they said yes...and then they brought me my discharge papers and the following day we made it down here...it was...I didn't know...shockingly...my mother decided she was going to fly out in an emergency and stay here for a week...*

Once Jaime reached the NICU at the Regional Referral Center, she felt better getting to see her baby again. She quickly gave her the nickname "little princess" and used this to refer to her baby throughout her personal journal entries.

Jaime wanted to do everything she could for her tiny baby, so she met with the lactation nurse to begin pumping breast milk. When it wasn't care time, Jaime sat at her baby's bedside and watched. Jaime was able to pick up quickly on the medical language

used by the staff. Her personal journal entries were used to document her thoughts as well as her baby's condition and growth:

*The lil' princess is doing so well. When she got weighed last night she weighed 2 pounds. I'm so proud of the progress she has given. She gets the IV out of her belly button in two more days. The breast pumping is a little overwhelming and tiring getting up every three hours. But I know that the princess is depending on me...she has had a few more heart rate drops but got them up on her own. She is sucking on her binky with pretty much no issues with forgetting to breathe.*

Jaime experienced feelings of depression and guilt about her early delivery. She wished that she could put her baby back into her womb to protect her and keep her safe. Jaime expressed sadness that her baby would be spending her first holidays in the NICU, *"It hurts that she will be in the hospital her first Halloween, Thanksgiving, and possibly Christmas and New Year's. I just want her home, it's too much to be 2 ½ hours away from home and family."*

Jaime at times has to return home for 1-2 weeks and is distressed to leave her baby. She disclosed her use of marijuana during her pregnancy. She was very remorseful that she hadn't made better choices. At the time, she lived in a large city and ran with people she admitted were not the best choice of friends. Jaime felt better once they moved to their current residence and became very involved in the church. She mentioned frequently in her journal that the church was praying for her baby and how much she loved being so involved.

Jaime waited anxiously for care times when she was able to touch her baby, change her diaper and feed her through a tube. She was careful to plan her time so that she is able to pump her breast milk so that she can feed it to her baby.

She takes great pride in how strong her baby is, *“She’s definitely a fighter. I just hope she does well enough to come home by her date she was expected...I’m so proud of her.”*

Jaime wrote expressions of love and hope in her journal:

*She’s got lots of people praying for her, she’s loved by many, and I know she’ll be ok...(this hospital) is by far the best hospital I have ever seen, and once she gets home the nursing staff will know how much we appreciate all of their help, and efforts.*

Jaime also developed close relationships with some of the nurses caring for her baby and her family. She would enter their names into her journal expressing her feelings of gratitude for the great care her baby was receiving.

She marked important milestones for her baby, such as getting the line out of her belly button and being able to do kangaroo care for the first time. She kept a very diligent timeline regarding her baby’s progression and development. Jaime references being a “mommy” very often and expresses “motherly” tasks, such as taking away her baby’s pacifier privileges when she dropped her heart rate.

Jaime would comment on nursing staff that she was not comfortable with taking care of her baby. She became quite upset one day when she entered the nursery, a nurse asked if they had stopped at the sink and washed their hands. This made Jaime quite mad and she came to my office to speak to me about the nurse. She didn’t want the nurse to take care of her baby because she had insulted her as a mother. The nurse made her feel like she didn’t know what she was doing...or what was best for her baby.

Jaime’s baby was finally stable enough for kangaroo care, *“our little girl is unbelievably amazing. It felt so good to be able to hold her. It was scary at first because she is so tiny...kangaroo care is going well...we took her out for an hour today.”*



Jaime held strong in her faith in God and that he was always watching over them, *“It was God’s plan for all of this, and he will never give us more than we can handle.”*

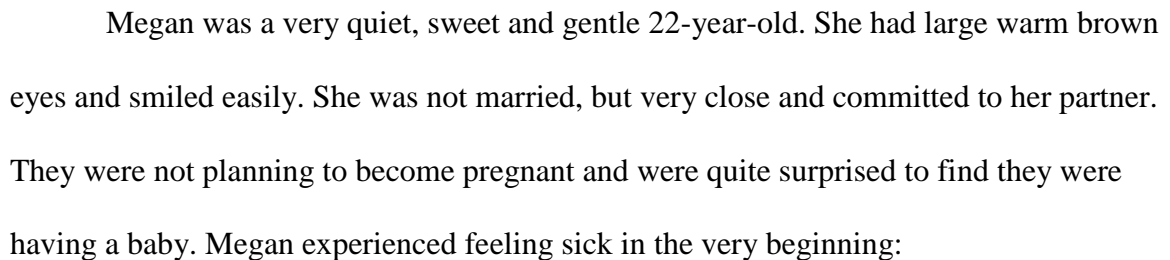
Jaime continued to have challenges of her own while staying at a local house run by a volunteer organization for those with family members in the hospital. Jaime and her partner were asked to leave because of being disrespectful to those in the house. She was devastated and felt the organization running the house was not being fair to them. Jaime stated that they were, *“not being very Godly...because they were in great need and had a baby in the NICU”* and others were being allowed to stay that didn’t need it. She talked about having to go back home with her partner and they would have to figure something out so they could see their baby, *“It really hurt to leave and go home, I wanted to cry, well I did cry, I’m worried, nervous, scared, and everything!”* Jaime had to continue to keep track of her baby’s progress by phone while she was at home.

Jaime remained quite vocal regarding her feelings of shock because of having her baby so early, so quickly, and not being able to see her baby after she delivered. She still couldn’t understand why it all happened. This continued throughout her time in the NICU.

Because Jaime smoked marijuana during her pregnancy she had to be evaluated by Child Protective Services (CPS). She realized she made poor choices and that meeting with CPS was part of making sure they were capable of caring for her baby. She disclosed having issues with being bi-polar, depression, and anxiety disorders and had been without her medication. Jaime made plans with her physician to get back on medication. She expressed the desire to go back in time and make better decisions.

In the end, Jaime was able to take her baby home. She and her partner were very excited on the day of discharge. Jaime seemed to really love her baby and I hope that she continues to make the best decisions for herself and her baby.

Megan



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Megan loved being pregnant and things were going well until she experienced pain at 23 weeks gestation:

*A couple of days before I went to the hospital December 17th and I think it was two days before that I went to go to the bathroom at night and like after I peed it felt like a real strong pain right in my groin...I thought that's odd...so I went to bed and didn't think anything of it....then I started getting some cramps and stuff the next day...the 17th I thought they were a little closer together and regular...so I started writing down when they would happen...how long it would last....and it started out about 45 min apart and got 20 and then by the time I got to the hospital it was about 7 minutes...I was worried...I was 23 and 6 days when I was in the hospital and they told me it wasn't viable and they wouldn't really do anything until 24 weeks.*

Megan had to be transferred from the County Hospital to the Regional Referral Center:

*I stayed here for 5 days holding her in... I was in reverse trendellenburg...it was horrible... to the point that I thought I was falling....I was not allowed to sit up...nothing...I could flip over...that was it.*

Megan had been told repeatedly that her baby was not yet viable, which kept her in a state of uncertainty regarding her baby, “I was devastated...didn't know if ...how she was going to be...how long she would stay in....and I kept hearing she's not viable...she's not viable.”

Despite all her efforts to maintain her pregnancy, she began to experience contractions:

*... the night before was probably like 3 in the morning...I'd woke up and it felt like I had gas pains...and I hadn't had any contractions or anything for quite a while....and just thought I had gas pains...cause they had actually let me eat food...some jello and tiny ice things....lived on that before they let me have food....and then about 3 in the morning I felt those gas pains so they gave me a gas pill...and then woke up and it was a little after 8 and they just kept getting stronger and stronger and stronger...and I knew something was not right here...and I called the nurses and they were like...oh you are kinda contracting and she was coming out feet first...the Dr. in the OR said that she had actually come out to her belly. It felt like it was like a matter of minutes I had gone from... I was 2 cm when I went to bed and I was 8 by the time they put me in the OR.*

Megan was prepped by the medical staff for a C-section:

*They put me out...I had a C-section...her heart rate dropped down to 20 and in all the process of finding out what's going on and they had to flip me on my left side and gave me this stuff to drink...and the Dr. said...well I guess she waited as long as she could...and then went off to the OR.*

After the delivery, Megan was moved to recovery where she could be continuously monitored:

*Nobody actually said anything as soon as I woke up....I was in this little room and I was freezing to death...and I asked if she was ok...and nobody really gave me an answer...and then...the dad had walked in and I asked him...and he showed me a picture of her...and she had a tube already in her mouth.*

Megan continued to have feelings of guilt that she somehow could have prevented the premature delivery of her baby:

*I've lightened up and I think that when I felt those first pains that first day I should have done something about it...crying....her grandma completely just beat herself up over everything because the day before I had the pains...no, it was the day after actually because I had asked her and she said they were bladder spasms...she's a nurse too...she is probably having bladder spasms where it is so full all the time...we went out shopping all day long walking around for hours...and I thought it was good walking around pregnant...whatever....and she feels like crap about that...she thinks since I walked so much...she made me walk....but that's not anything anybody could help I think...I think she was coming whether we did anything or not.*

Once Megan stabilized after recovery, she was able to go to the NICU to see her baby for the first time, “(first thoughts) she was ok....she was alive...and so tiny...I cried...she was so tiny and I was so scared...I don't really know how to explain it...I was just afraid she wasn't going to make it...”

Her partner told her about what happened during the delivery when Megan was under general anesthesia:

*The dad said they had taken her out of me and they put her on the table and then intubated her...so she didn't do anything...”(touching for the first time) yeah....I was scared....I was afraid I was putting germs on her...*

When asked if she had ever seen anything that small, she responded, *“my baby doll...that's about it.”*

Megan studied every inch of her baby looking at her features, relating them back to her and her partner's characteristics, *“She is all dad... (laughing)...all dad...I can't find one thing like me...she has nothin' like me...I hope she will have my dimples!”*

Megan reflected on having to wait to see her baby and how difficult it was, *“yes...it was the longest...I don't know how many hours it was...she was born at 9:30 and it was 8 hours before seeing her.”*

She recalled the first time she was able to interact with her baby:

*I was scared to death to change her diaper for the first time...I mean I had changed millions of diapers before...but...I mean her...she was this big (showing how small)...got more comfortable...love to give her baths.*

Megan loved to be able to touch her baby and do her care, but felt like at times the nurses just didn't want to bother with letting her do things, *“I kinda feel like the nurses still do a lot of it...they try to do more of it instead of letting me or asking me...if I usually do this.”*

When asked if her medical experience helped her with having a baby in the NICU, Megan responded, *“I'm a CNA...but it has nothing to do with babies....I didn't work at all during my pregnancy....I just don't know anything really about babies and their numbers or where they need to be at...”*

Megan continued to care for her baby in ways that she was able such as washing her clothes, *“I am very OCD about germs...I wash all her clothes in Dreft and put it in a bag and bring it here so that it doesn't touch anything...”* I observed Megan many times at her baby's bedside unpacking the washed clothes from home and placing them

carefully in her drawer at the hospital. She made sure that her clothes were perfectly folded, with matching bows and socks.

She developed a very close relationship with her primary nurse and trusted the care she provided. She liked to share special moments that would occur when her primary was not working, *“today is her 2 month birthday I have her a little tutu to put on...her primary isn't here until tomorrow night...I will take a picture to show her....my cousin made it for her...she is already spoiled.”*

As time went on, Megan became frustrated when the nursing staff would have completed the very care that she longed for and waited to be able to do for her baby. She felt like her job had been taken from her:

*It's hard at times because like a couple of times we looked really forward to the care times...cause that is the only time you can do your motherly duties...I hate when we come here and it's already been done...kinda like she has a bunch of mothers....miss that bond... (crying)....you can only see them certain times of the day... (crying)...waiting to get back when we leave her...*

Megan pumped her breast milk knowing this was something only she could provide for her baby. She loved to be able to give her baby the food she needed to grow strong, however, after time her supply began to diminish:

*It (pumping) makes me feel pretty good...I know that her belly is a little sensitive...and I don't want her to have to go on formula because I couldn't make enough...I've actually started to decrease my milk supply...I pump pretty frequently and I eat high fiber foods... and skin to skin... and it's still not increasing my supply...I am thinking it might be the pump because I can still get milk out and I still feel full...lactation gave me a new kit to see if that helped anything...I used to make two full bottles and now I am lucky to get 30 mls.*

Megan planned for when she would be able to take her baby home. She incorporated strict infection control practices she learned while in the NICU into her home to keep her baby safe:

*When she gets home...never put her down...she won't know what a bassinette or crib is....oh yeah...everybody will wash their hands and sanitize before they touch her...and put a receiving blanket on if they smoke...if they cough...she won't be laying where they cough...have you been around anybody who might be sick....especially his mom...she is an LPN and she is all about the germs....combatting the germs all day long...makes me feel better.*

As the baby's condition began to improve, Megan had to focus her efforts on moving to another state to be near her family. This was quite hard on her being away from her baby so much, as many trips were required between the two states to get their things in place and ready for the baby:

*...we are actually moving back to where all of our family is...we are hoping to do it before the baby comes home....so we don't have to put her through a move...so she is settled. Whenever we go ...we swing by here for a couple of minutes and say hi to her and then swing in again on our way back... it's about 3 hours...yeah....so she is like right in the middle...(laughing with tears in her eyes).*

Megan described when her baby was diagnosed with pneumonia and had to go back on the ventilator. Her baby had been weaning off oxygen, when suddenly her requirements increased. Megan blamed herself for potentially causing her baby to get sick:

*She (her baby) had gotten pneumonia...Ureaplasma...that kinda set her back for a while...she was on the vent for 6 weeks because of that....I felt it was my fault because of me not knowing that her membranes were already coming out and I had taken a bath...so I could have introduced germs in there I felt that I had gotten her sick and it just happened to come out at that time and her getting sick...*

Megan was worried about her baby being back on the ventilator, and frustrated because she could not hold her to comfort her during this time. She had been used to getting to hold and feed her, but now had to sit and wait. Her independence in caring for her baby was taken away because she was sick. Once again, Megan was required to take cues from the nursing staff as to when she could change her baby's diaper and take her temperature. She didn't like seeing how fragile her baby still was even though she had



grown bigger. Megan was even more committed to making sure family washed their hands and used hand sanitizer once she took her baby home. She knew that she needed to keep her fragile baby safe once she had her home.

Megan described what would have to improve with her baby before she could take her home:

*....still kinda feel ...not as much...but waiting until she can take a bottle and to take that next step....and there's a lot involved with that...she has to get her pressures down and it's just waiting...for all that to happen...waiting for her to come home....*

Megan had waited a very long time to take her baby home, however, when she arrived in the unit she was told that her baby had dropped her heart rate during the night and she couldn't be discharged that day. She was devastated and began to cry, while her partner became very angry. The physicians explained that she would have to wait 5 days to be sure that she would not experience any more drops in her heart rate. Megan and her partner were devastated to learn that they would not be taking their baby home, and it was hard for them to concentrate on what was being said. Finally an alternate plan was developed that would allow Megan to be with her baby and have the required medical supervision needed. They were transferred to Pediatric Acute Care where Megan and her baby could be in a room together while her infant was being monitored. Megan would get to care for her baby and the nursing staff would only take vital signs and monitor her heart rate continuously. This was comforting to Megan and helped her deal with the fact that she wouldn't be taking her baby home that day.

The five days were wonderfully uneventful and Megan was able to take her baby home. She really liked having the time with her in the hospital to be able to completely

care for her baby, with medical staff around in case they needed anything. She felt more than ready to take her baby home and be her mother.

## CHAPTER NINE

### Findings

To begin data analysis the constant comparative method was used because it allowed for simultaneous review of both previously collected data and new data throughout the research process. Emerging themes and concepts formed a conceptual theoretical model (see Figure 9.1) illustrating the process used to develop the mother role while in the NICU. This theoretical model includes five stages that occur when a first-time mother develops her role within the NICU. The stages of progression within the model are “Threat”, “Surreal”, “Watching”, “Normalcy”, and “Home”. The progression through the stages is not necessarily linear in nature, but rather a fluid progression whereby the mother may revert back to a previous stage at any point, usually attributed to what is referred to as a “Disruptive Event”. Also represented in this conceptual model is the concept of “waiting”. “Waiting” was found to be important to represent in the model because it is intricately woven into every stage in the model and has a significant impact on the mother.

#### **Threat**

The first stage “Threat” involves facing the questionable viability of the pregnancy. This involves serious health concerns for both the fetus and the mother. The woman has concerns regarding her own health, but only as it relates to the baby. Shelley had issues with her blood pressure that required frequent monitoring. She woke up with excruciating back pain and knew that something was very wrong. She recalled the ride to the hospital:

*I remember it seemed like it was just taking forever to get there (the hospital) and in the meantime, I was sure in my mind that either I was losing this baby or I was dying but both options seemed very possible to me and I was terrified.*

This period causes stress on the family unit emotionally and at times economically. Often times the pregnant woman is unable to consistently work due to required bed rest and hospital monitoring. This can cause financial strain which adds to the stress of the pregnancy. Bailey and the father of her baby lived in separate houses when she became pregnant. She was monitored closely because of cervical funneling and required bed rest at times, “*So then I reached the depressed stage...he had to take on my payment on my house and his house...so I have never seen him...so it was just me...most of the time.*”

The mother-to-be feels helpless and vulnerable because she is not able to control and stabilize her pregnancy. She feels frustration when she adheres to the physician’s orders and still continues to experience the adverse health condition that threatens her pregnancy. Most of the mothers continued to blame themselves throughout the hospitalization for the premature birth of their baby and wondered why they couldn’t maintain the pregnancy. They all felt a strong sense of failure. Megan expressed feelings of remorse, “*...I think that when I felt those first pains that first day I should have done something about it... (crying).*”

For these women, the delivery is not the event they have dreamed about, but is filled with uncertainty. Bailey recalls her delivery as chaotic and severely lacking in the magical delivery moment:

*that’s what you’ve been waiting...in the TLC shows...that is like the big moment...and you don’t get that...and then you are like anticipating and wanting to hear crying...don’t know what to expect...he was so small...so, it was just like unreal...it was really so surreal to me.*

They worry if their baby will be able to survive. It is about more than just counting ten fingers and ten toes; it's about taking the first breath. Megan began having contractions and began recording the time apart:

*It started out about 45 minutes apart and got to 20 and by the time I got to the hospital it was about 7 minutes...I was worried...I was 23 weeks and 6 days when I was in the hospital and they told me it wasn't viable and they wouldn't really do anything until 24 weeks.*

Once the baby has delivered, the mother is filled with self-blame for not being able to maintain the pregnancy. They feel that somehow they have failed their baby by not being able to keep them safe. The sequence of events during the delivery can occur rapidly leaving the mother with many questions. The infant may require swift medical attention and transfer to an NICU. This leads to the next stage of the model called "Surreal".

### **Surreal**

The second stage "Surreal" refers to the initial period in the Neonatal Intensive Care Unit. Not all cities or local counties have an NICU so mothers may have to travel to a strange new town that could potentially be hundreds of miles from home. Most families have never been in an NICU and are unfamiliar with the environment, equipment, alarms and terminology used when caring for these infants. The new mother becomes overwhelmed with information regarding her baby's condition and the rules that guide everything they can and can't do while in the unit. Many times mothers were not able to see their babies at delivery because of the critical need to resuscitate and transport quickly to the unit to continue life-saving measures. The baby might look different than the mother imagined, seeming extremely fragile depending on the severity of prematurity. Shelley described the first time she saw her premature baby, "*Walking to the*

*NICU seemed to take forever... I remember going in for the first time to see my baby boy...I have never seen nor imagined something that small and fragile.”* The mother is afraid to touch the baby and to emotionally attach thinking this may protect her in some small way if the baby were to not survive. The feeling of helplessness continues as she realizes that she still has no control over what happens to her baby. She continues to deal with blaming herself for not being able to maintain the pregnancy and to keep her baby safe. Nicole expressed feelings of blaming herself because, *“I didn’t say anything...if I would have said something earlier...maybe it wouldn’t have happened...maybe I would still be carrying him around.”*

The new mother also grieves the loss of her physical state of being pregnant. She did not get to experience the joy of being pregnant such as walking out in public and being recognized as being pregnant. Her trips to the doctor were filled with anxiety and hearing bad news, not joyful about her and the baby’s progress toward the big event. Many of the new mothers delivered before their baby shower was even planned, so they were not able to celebrate and receive gifts to welcome the baby. Even simply getting to wear maternity clothes and to watch her stomach grow were rites of passage cut very short.

*You didn’t get to feel pregnant because of all the complications...so you never got the baby shower...none of that...you know nothing big...my stomach got big, but not to the OMG...you are really big and pregnant...never got to that stage.*

Once the new mother begins to accept the reality of the situation, she moves to the next stage of the model, “Watching”.

## Watching

“Watching” is the third stage in the model of becoming a mother in the NICU.

The new mother watches the baby endless amounts of time. Shelley entered the following in her journal, “*all I could do now was stare at him through his little box.*” The new mother watches the nursing staff and how they provide care to her baby. Also watched and studied is the terminology used by the medical staff to describe her baby’s condition. She quickly becomes knowledgeable about her baby’s labs, lung status, ventilator or oxygen settings, feeding amounts and their daily weight. Nicole’s journal was evidence of this as she kept meticulous records of her baby’s progress. She used her journal not only for the purpose of the study, but to relay the day’s information to her family and friends.

The new mother begins to practice taking care of her baby with the guidance and support of the nursing staff. During this period, she will wait for the nursing staff to direct her as to what time to start her baby’s care and what tasks will be done in what order.

Bailey expressed this feeling of uncertainty:

*Because everything is so intimidating in the beginning...you ask questions...even just to put your hands in the side of the incubator...you ask like 1000 times...all the rules...you are waiting for the time to come for care...and I am waiting to check his temperature and flip him over...most of the time you are just sitting there waiting.*

Mothers in the NICU begin to develop trust relationships with certain members of the care team and prefer they take care of her baby. This is the stage that the new mother begins to really develop her role as she begins to take ownership of her baby:

*It’s just like you know I’ve got one particular nurse that I don’t care for...and I made it be known...and she’s no longer taking care of him...well she doesn’t need to be taking care of him. I’ve not had any problems with any other nurses...she was just...might have been having an off night.*

During this stage she becomes well versed about her baby's medical condition, and how to advocate for her baby based on what she feels the baby needs:

*And when the doctor came in and I told her...he doesn't look right...and she said...well, he doesn't look out of the ordinary to me...and I was like...I know him...I am here every day...and she ordered his blood work and his blood was low...he didn't have enough in his system...and he had to get a second transfusion.*

By this time, the new mother has learned about her baby and the NICU. She has folded this experience into her life and developed a new normal. This leads to the next stage of the model referred to as "Normalcy".

### **Normalcy**

This next stage takes place when the new mother has established a routine, and the days in the unit are more predictable. She reaches a stage of "Normalcy". The baby during this stage is stable and growing. This phase is not based on the level of care the baby requires but rather the stable predictable flow of events. For example, the baby may be intubated but is stable on the ventilator. During this stage, the new mother is able to function a little more independently. She knows the care times for her baby and begins getting supplies ready for care time so that she can do her "mothering tasks". Bailey visited daily and knew her baby well. She delighted in the fact that she could function more independently.

*Now it's more of a routine down pat...confident in what you are doing...like the nurse says, "do you need help?" and I say...I got this!" Used to be I would ask every time...can I open this door...move this over...constantly asking questions...cause you didn't know what to do...or stressing him out...so now like we have been doing this for 2 months now...it's like we are all hands on...we don't ask for help...or ask questions...we just go ahead and start getting stuff out to get ready for his care. It's totally different from before when I look back now...I didn't think we would get to this point...it seemed like it would take forever...so far away...but now it's here.*



When family members come to visit, the new mother is the expert regarding her baby and she instructs them on everything from how to wash up when entering the unit, to what the baby prefers during care time:

*She (grandmother) is coming today...our baby came at the right time. She is 3.5 hours away and saves her time to be able to come for a couple of days...I love to show him off and the things he does...and just families walk around here...so he comes from a big family...so I tell them any time they want to come by and see him...just come on and I will show you my baby.*

The new mother is happy to celebrate the “firsts” for her baby such as the first hair bow, the first time they opened their eyes, the first pacifier and when the baby reaches 1000grams. These celebrated “firsts” are very different from a full term baby’s firsts, but every bit as important. Jaime taped her baby’s first headband with a bow to the first page of her journal for a keepsake. The bow was a light pink satin ribbon and the headband showed how very small her baby was when she was born. Jaime reminisced about how much her baby had grown and exclaimed that she had already outgrown the bow! First bottles are also a big deal in the NICU and a source of pride and celebration among the nursing staff and the family. The bottles are often given to the mother as a keepsake after being washed, dated and decorated with a bow.

Because the new mother during this stage is calm and relaxed, she is able to look outside of her own situation and begin to notice other families and babies in the NICU. She is able to provide advice and share her experience with new families, trying to help them cope with the NICU environment. She also notices the plight of others:

*And then you see the parents you know...it’s like...the ones who don’t pay attention...they aren’t here...they don’t see...they are here but not here...they take them home and they end up right back in here...because they take into consideration...it’s their baby...but they don’t consider...that is a baby...and I’m not one to judge...what a parent should be...but they shouldn’t have been parents...*

She smiles more during this period of time and takes great pride in her baby and their accomplishments. The new mother will brag to others about how well her baby is doing and how strong they are to have made it through much adversity:

*We have been here every day...and our faith and hearing your voice...and he is kinda getting used to you...I feel it has (made) a big difference in how he's doing and developing...that's just my little theory...I honestly do...sometimes you don't know...some people can't be here as much...I really think so...cause he has done really well.*

During this stage, the mother begins to refer to the mother and baby dyad as “we” in her statements about her baby, “*hopefully in the next couple of weeks we can be holding our temperature...it's a goal...and if he doesn't reach it its ok...*” This was very evident during my observations when asking how the mother was doing. Her comments revolved around the idea that if the baby was okay, then she was okay. This symbolizes that the mother has become very “in tune” with her baby and how he or she was doing.

This period of stability eventually leads to the mother preparing for the next stage of the model, “Home”.

### **Home**

The last stage is “home” in developing the mother role while in the NICU. The baby continues to grow and stabilize. The medical providers begin to discuss and plan for discharge making sure the criteria are met. During this period, the mother begins to prepare the home environment for the baby. The new mothers put their home life on hold up to this time and when faced with the realization that their baby is almost ready to come home, they are hit with the reality of needing to prepare. They spend time away from the unit to clean their house and set up for the baby. Some even move to a new place, requiring a significant amount of time away from their baby:

*We are in the process of looking for a new place...it's crazy...I promise you the day that we move will be the day we come home...I said to dad...don't jinx us...we thought we had more time of him on cpap...but hopefully we can have the new place in order...now we are thinking in a couple of weeks we need to find a place...so that we can clean...so at home we are just trying to get everything ready and packed up to move...sweating bullets now...we are rushing now...and we are thinking it could be tomorrow...*

The new mother is torn between wanting to stay at the hospital, but knowing she must make her home clean and ready. She looks very happy, but tired during this period because of trying to fit everything into a day. Her plans include incorporating what she has learned from the NICU into her home routine. Some new mothers keep it to just using hand sanitizer and limiting visitors for the first few months after bringing baby home, and others closely imitate the routine of the unit including keeping a “chart” on their baby to document feedings, medicines and diapers:

*Oh yeah, everybody will wash their hands and sanitize before they touch her...and put a receiving blanket on if they smoke...if they cough...she won't be laying where they cough...(and ask) have you been around anybody who might be sick...*

The new mother experiences being excited yet scared to leave the NICU. They are thrilled at the thought of getting their baby home which has always been the goal; however, they are scared to only have their knowledge to make decisions regarding the baby. They can't imagine caring for their baby without the staff of the NICU present; even though they know it is coming. The achievement of their goal to get their baby home is the very thing that scares them most:

*You get that pride...conceited pride...(laughing)...so like I (am) really happy...time is good...cause you have your concerns...and the big thing is probably for me once I'm home is like...what to do then...because here you have unlimited hands...but you know you are going to get in your own routine...but what to do once something happens...and who to call...or some of that...and I know like one nurse lives in my town...I may need you to slide on down to my house...just to recognize the face and hear a voice.*

With discharge, the new mother assumes the role as the only mother. She becomes the expert regarding her baby. This is when she achieves her mother role:

*I hear people say how I better enjoy this chance to rest while he is in the NICU nursery because when he gets home I will never sleep...but I don't need sleep. I need him. I feel like anyone who has a baby before its time must feel the same as we do. I am not totally prepared as far as material things go, but we are getting there. I have to get a new car seat because he needs a 4 pound plus and the one we got was 5 plus, but I don't mind I am just so ready to take him home and be the only voice he wants to hear.*

Not every mother in the NICU gets to take her baby home. Medically fragile babies face many challenges with some not able to survive. The participants for this study were selected based on the viability of their baby, but this was not a guarantee. There is potential for a baby in the NICU to experience a decline in their condition referred to in the next section as a disruptive event. All of the mothers in this study were able to take their baby home.

### **Disruptive Event**

The plight of the infant admitted to the NICU is very precarious and uncertain. Because of this, we must include in the model the potential for a disruptive event. This event can occur at any point during the hospitalization in the NICU. A disruptive event may never occur, or may occur multiple times. The degree of severity may also vary depending on the infant's condition at the time of the event and the etiology of the event itself. The disruptive event begins when the baby experiences deterioration in their current condition causing a significant setback in current treatment or progress. When dealing with a severe deterioration, the mother experiences shock and disbelief at how quickly it occurred. Bailey experienced a severe deterioration in her baby's condition:

*(heavy sigh)...it was unreal...we didn't know what was going on...he just kept desatin' and desatin'...and everything went just downhill...and it was a shock for*

*everybody...but they came up to the chest x-ray...he had desatted so much...and he never did that stuff...it definitely was heartbreaking...we went for days and just didn't know.*

This event causes the mother to revert back to earlier stages in the model because she is overwhelmed and returns to feeling she could potentially lose her baby. She mourns the loss of all the progress her baby made, only to be back at the beginning all over again. She again feels helpless and has to learn new terminology. She withdraws inward and can only see her baby. She is void of all expression and simply stares at her baby. She stands vigil at the bedside fearing that if she leaves something terrible will happen. Devastated at how fragile her baby still is, and worries that her baby will never be strong enough to make it out of the NICU. Bailey expressed her fears and the impact of this situation:

*...and I felt like it was snatched away...because then they put him on the vent...and we couldn't get him out...I got him out twice when he was on the vent...with many days between...so it was just like...we were back at stage one...kinda how I feel. I had been able to do all his care...but then I couldn't do his care...and then when we would get to...they would hover and you felt like you were going to do something wrong...it felt like completely starting all over from day one...that was very depressing...it was pretty bad cause then you were like...then you don't know if you are going to get to take him home or not...and you could just see that he had no strength...even after growing so much.*

She wonders if she caused the deterioration in any way, and again feels that she didn't protect her baby:

*Cause I felt like I had gotten him sick...cause he had pneumonia...and he was completely going purple...it was unreal...me and dad were really hurt...so then we were like how did he get it...and how did we get it...we still don't know how he got sick.*

The new mother wonders if there will be additional special needs her baby will have based on this current set back:

*We are about to start a new journey...one that no one knows about...so it was just more about what could we do now...to help him and his development later...that*

*was our main goal...because I knew it was going to be hard...and he already is going to have milestones because of being premature...and we just wanted to find out what we could do as parents.*

### **Waiting**

An overarching theme that traverses each stage of the model is “waiting”. During her pregnancy, the expectant mother waits to see if her contractions will stop, waits to see if her blood pressure will improve, and waits to see if she will maintain the pregnancy or delivery early:

*It was more stress then anything because you didn't know what to expect next...you didn't know what was next...so then they were like, well, we'll try a cerclage and that will help...but then they're like...but there's not a guarantee...so then you're like oh gosh...oh what does this actually mean...like, what's going to happen next...it's just really stressful...but they tell you not to stress...but it's hard not to because you really didn't know...and then times I would be so scared being at home by myself...then I'm like I could go into labor at any time and I am here by myself...that was the big thing...a lotta times I would cramp so bad...is this contractions?...but I didn't know what contractions were...so I was just lost...and I would look up stuff on you tube and google...and you just couldn't find anything.*

During the delivery, she waits to hear her baby cry and to be able to see her baby for the first time. Bailey's delivery was rushed and chaotic:

*It was so fast, they took him...so it was just like, that's what you've been waiting...in the TLC shows...that is like the big moment...and you don't get that...and then you are like anticipating and wanting to hear crying...don't know what to expect...he was so small...but dad did go in the other room and did hear him cry...but I couldn't hear anything 'cause I was still concentrating.*

After the delivery, the new mother waits to go into the NICU, waits for her nurse to tell her about her baby, and waits to be able to touch her baby for the first time. Shelley didn't know what to expect when she first entered the NICU to see her baby, but never expected that she would have to be so hands off:

*I don't really know how I expected his birth would be, but I never prepared for the idea that I wouldn't be able to touch him, hold him, feed him, or even change him. All I could do now was stare at him through his little box.*

The new mother waits for labs to come back, waits to see her baby's eyes, waits to see if her baby will live. Megan recounts her feelings the first time she saw her baby eight hours after delivery, *"I cried...she was so tiny and I was so scared...I don't really know how to explain it...I was just afraid she wasn't going to make it."*

She waits for the next care time, waits for the baby to get better, waits for the baby to wean off the ventilator, waits for her baby to wean off oxygen, and waits to be able to take her baby home. Nicole found it very difficult to see others get to take their baby home while realizing her baby still needed to stay in the NICU:

*It's easier than at the beginning...because you know...I know I am here for him...I know he's here for a reason...and then don't get me wrong...I would never mean anything bad by this...but you see these other moms go home with their baby...like I said one of the parents was in our room...she was here for 10 days...and you're so happy for them...but you resent them at the same time...it don't seem fair...and I know you're not supposed to question the man above...but I wonder what I did so bad to be in this situation...and I am just so ready to go home...when am I going to get to leave?*

Waiting is a significant theme throughout the model, with the most significant subtheme being "waiting to mother". Nicole expressed her feelings during an interview:

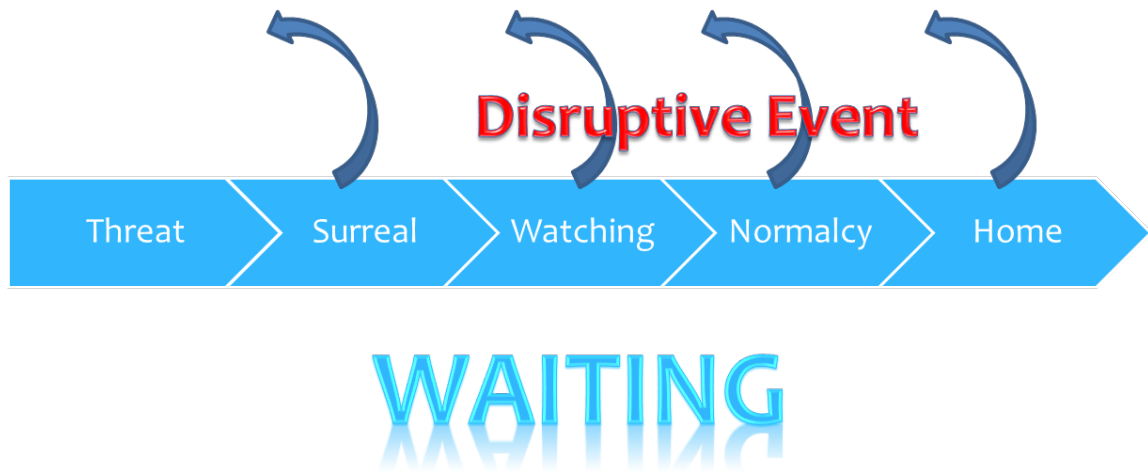
*The biggest thing is I'm waiting to be his mom...I know he's here and I know he's not supposed to be here(yet)...I'm not really going to be able to be his mom until I take him home...because I mean he has 125 moms here...and I'm just one of them...because the nurses are doing the same thing I'm doing...yeah I'm hands on...but he's not mine...he's not mine until I am able to take him home...it's always a waiting game...69 days.*

Mothers' progress through the stages of the model at their own pace based on their own individual experience. Not all mothers successfully complete the development of their mother role. This model is not to provide an exact "map" to motherhood, but rather to share the progressive stages experienced by the mothers in this study.

In the last chapter, I will summarize this research study by reviewing the specific aims, strengths, limitations and indications for further study. Findings will be shared that support published literature and those that are unique to this study.



Figure 9.1 Theoretical Model of Mother Role Development in the NICU



## CHAPTER TEN

### Conclusion

The purpose of this dissertation study was to explore the process of developing the mother role among first-time mothers having a premature baby in the NICU. The specific aims included (1) describing the disruption in the individual's preconceived idea of being a mother, (2) exploring specific strategies that support the mother in the development of her role while in the NICU, (3) describing the mother's perception of her role during physiologic changes in her baby, (4) examining the mother's evaluation of her mother-role success (5) developing a deeper understanding of the process of developing the role of mother while in the NICU, and (6) constructing a theoretical model to illustrate the process of becoming a mother while in the NICU.

#### **Disruption in Preconceived Ideas of Being a Mother**

By using a qualitative grounded theory methodology, I was able to explore the new mother's disruption in the perception of what her role should be through in-person interviews, personal journal data and direct observation recorded in my own notes. The reality of the NICU seemed to frustrate the new mothers because they were not able to express their role. Instead, they were only able to sit at the bedside of their tiny baby and watch others provide care and life-saving technology of which they knew nothing about. The new mother felt inadequate and unprepared to care for her baby, or to even know what her baby would need, which mirrored her feelings during her pregnancy if threatened.

### **Strategies that Support Development of Mother Role**

The second specific aim included exploring strategies that supported the mother in the development of her role. Mothers expressed the importance of “hands on” care such as changing the diaper, pumping their breast milk, feeding their baby, giving a bath, and kangaroo care as important to their role. They felt it was very important to know what was medically happening to their baby and to be able to speak the language of the unit. The mothers felt their role was threatened or infringed upon when the nurse caring for their baby would do their care before they arrived. This would lead to intense emotion and leave the mother feeling quite frustrated and unable to express her role while in the NICU.

### **Perception of Mother’s Role During Physiologic Changes in Her Baby**

Another identified study aim was to describe the mother’s perception of her role during physiologic changes in her baby. Positive perceptions occurred when there was an improvement or advancement in the baby’s condition. This led the mother to be able to interact more with her baby, which consequently let her express her role with a degree of independence. This also encouraged the new mother in her progression toward home which was the ultimate goal. Conversely, the mother was adversely affected when the baby’s condition declined. The mother found herself back at the beginning lacking the knowledge to understand what was happening, and being limited in her interaction and care for her baby. The new mother confronted fears about whether her baby would survive, or experience a life-limiting condition. Feelings of helplessness and despair characterized her feelings during this event along with a loss in many of the aspects of her role.

### **Mother's Evaluation of Mother-Role Success**

The fourth aim involved examining the mother's evaluation of her mother-role success. Mothers' ability to care for their infant occurred on many different levels and involved many aspects of the baby's condition. Mother's expressed feelings of success in their mother role development when they were able to provide aspects of their baby's care, successfully provide an adequate supply of breast milk, and do kangaroo care. Their evaluation of their mother role development was negative when they were not able to provide care, or the nursing staff would provide the care before the mother returned to the unit.

### **Understanding of the Process of Developing the Mother Role in the NICU**

Developing a deeper understanding of the process of developing the role of mother while in the NICU was another aim of this study and is why I chose to use a grounded theory method. During my 28 years in the NICU, I have worked with mothers and watched them during the course of their hospitalization. The changes I witnessed seemed to indicate that the mothers went through a process of role development. This study collected data in "real time", having the mothers use a personal journal that was "event driven". Interviews of the mothers took place during the hospitalization period and were used to validate the personal journal data. This provided tracking of the development of the mother role along with the surrounding events that either supported or suppressed the mother's progress while in the NICU.

### **Theoretical Model of the Process of Developing the Mother Role in the NICU**

Constructing a theoretical model to illustrate the process of becoming a mother while in the NICU was the final aim of this study. Once the information was collected

from study participants, common themes and concepts began to form into stages. It became very clear that there was a progression of mother role development while in the NICU. The new mothers included in this study seemed to follow a very similar path to developing their mother role and expressed many of the same frustrations and joys to support the staging of progression. Once the stages were formed, the model was constructed to show how the mother moves through the stages and how the concept of waiting affects each stage of the model. The model also shows the possibility of a disruptive event and how this can impact the mother's progression of her role development.

It is important to evaluate how this model supports current literature and what new contributions are made to our knowledge of mother role development while in the NICU. The model developed in this dissertation work supports concepts in the literature of the mother feeling unprepared and overwhelmed by the NICU environment, the need to feel ownership by knowing information regarding her baby, provide care giving activities to express her mother role and feeling threatened by the role of the nurse (Bialoskurski, Cox, & Hayes, 1999; Fenwick, Barclay, & Schmied, 2001, 2008; Heermann, Wilson, & Wilhelm, 2005; Hurst, 2001; Lee, Long, & Boore, 2009).

A concept revealed through my dissertation work is the experience of the new mother during her pregnancy and the impact on her role development. This period of time is important because of the expression of stress, worry, and depression of the mother which impacts her during the pregnancy as well as during the NICU experience. This period of time can cause stress on relationships, finances, and emotions. The pregnant woman worries about the viability of her pregnancy and therefore may not prepare for the

baby or her role as mother. She carries this experience with her as she moves into the NICU experience and brings a very unstable foundation of worry, guilt, potential loss and uncertainty with her.

This research provides a model of the process of internal work used by a mother to prepare for her role while in the NICU. Preparing to mother a medically fragile baby requires very different work when compared with mothering a term, healthy baby. The intense “learning” of terms, conditions, staff, and provision of care is quite amazing and needs our recognition. The stages developed in this research, “threat”, “surreal”, “watching”, “normalcy”, and “home” categorize the work by the mother to develop her role while in the NICU. The amount of time in each stage and the progression through the stages can vary between individuals and is directly related to the condition of the baby.

The foundational component of this research is the concept of waiting. This work presents the idea of “waiting” and its importance as it takes place continuously throughout the model. The mother is in a state of constantly waiting from pregnancy through to discharge from the NICU to home. There is much frustration, worry, and uncertainty that accompany these periods of time. This is a key concept for healthcare professionals to understand so that they are better equipped to assist the mother in dealing with these periods of waiting.

The disruptive event described in this dissertation work is also a new concept to the body of research on mother role development. The literature to date has not described in detail the impact of a disruptive event on the mother and how this impacts her role development. While the focus in the NICU is on the baby during this type of event, it is

critical for the healthcare staff to realize the impact on the mother to help to support her through this critical period of time.

### **Challenges**

This dissertation work was not without challenges such as the recruitment of participants. Mothers in the NICU are stressed and worried about their baby. It is for this reason that careful consideration was used when approaching a potential study participant. The condition of the baby was determined before approaching a mother to participate, but even with this consideration, some mothers were not interested in the study. This caused me to constantly reevaluate the methods chosen for my study, and each time I came back to the importance of collecting the data as close to the actual events as possible. The data collected is rich and therefore valuable in understanding the process of mother role development so that we as healthcare providers can develop interventions that will support and provide the experiences the mother requires for successful development of her role while in the NICU.

Another challenge I personally experienced was balancing the dual role of nurse researcher and nurse manager. It was important for me to maintain the perfect mix of these roles to remain successful in both. There were times that the mothers would approach me as the researcher, and other times as the nurse manager. It was important that I maintain their confidentiality during the discussions outside the parameter of this study as well as the knowledge I obtained through my position as the manager. I paid very careful attention to staying true to the information and data they shared during our interviews and their personal journals for use in this research.

## **Successes**

Along with the challenges of this dissertation work, it is just as important to mention the successes. One success was the data obtained from the personal journals of the participants. Initially I was hesitant to include personal journals as a data collection method in this study. I wondered if the study participants would use the journals to log entries, or if they would find this burdensome. I was thrilled to see that the mothers were delighted to have the journal and enthusiastically entered their data. The new mothers actively engaged in personal journaling and were open and expressive with their feelings and thoughts throughout the process. I also inwardly hoped this would help them during their hospitalization, not only giving them something to do while “waiting” at their baby’s bedside for the next care time, but also help in getting their feelings out and to be able to have a means to express and then discuss with me what they were experiencing. One mother remarked how much she enjoyed our talks, and how it had helped her during her stay in the NICU. I was overjoyed at the aspect that I was able to help them in some way...which really was to just listen.

Not only was the data in the personal journals extensive, it allowed for data collection in real time. It was important to collect the data as it was occurring to capture the true thoughts and feelings of the mothers during a very intensive experience. This method of data collection supported the ability to stage the progression of the mother role development while in the NICU in the sequence that it occurred.

Another success of this study was the trust developed with the mothers in this study. I am amazed at how open the new mothers were with me and shared their deepest thoughts. We were able to establish a relationship based on trust which is foundational to the qualitative process. I worried about the my ability to develop a trusting relationship



with the mother whose in-person interview lasted 20 minutes, but found out very quickly that she was able to use her personal journal instead and expressed feelings of gratitude toward the nursing staff caring for her baby as well as deep expression of her experience.

Data saturation was also a success for this dissertation work. Data saturation is a prevalent concept in qualitative research that supports the findings. The question frequently asked is how to “know” when the amount of data and number of participants enrolled is sufficient. This is achieved when there is a redundancy of the data collected to support the concepts and themes that have been identified in the research. This dissertation work provided repetition of conceptual data outlining the process of mother role development to support the findings, thus saturation of the data was achieved allowing for a successful conclusion of the research (Charmaz, 2006).

### **Implications for Future Research**

Given the current sample of five participants, it would be important to engage mothers of various ages and geographic locations whose babies are in the NICU to validate the findings of this study. We need to know more about what the mother experiences during a threatened pregnancy and while in the NICU with regards to her mother role development so that we as healthcare providers can provide support and apply interventions to help her through every stage. The theoretical model developed needs additional research with new mothers to see if the stages hold true. Because this study took place in one NICU, it would also be important to see how mothers in other NICUs experience their mother role development and if the model applies to their development.

It is important to use the findings of this study to begin to educate healthcare providers in the NICU about the lived experiences of these mothers. Interventions will need to be developed and tested that support a mother's progress regarding her role while in the unit. Educational materials are needed to be developed to help the mothers understand what it is they are experiencing, and that they are not alone. They need to understand that other mothers have similar feelings, and that these feelings are normal for the situation. The role of family counselor should be considered by Children's Hospitals to provide the needed support to families because of the intense nature of their experience. Neonatologists and Nurses in the NICU provide support to our families, but a trained family counselor would take the ability to support to a much deeper level as the mother would be their primary focus.

This dissertation work focused on the new mother and the process of developing her role, but additional research needs to expand to the experience of mothers after discharge from the NICU, mothers who already have children, and to the process of father role development. As the field of Neonatology continues to provide lifesaving therapies successfully for the smallest of babies, we must continue to study how to best support the mother and the family during this intense experience. The findings in this study begin to address the gaps in the literature regarding real time data collection, the effect of a threatened pregnancy, understanding the internal work by the mother, the impact of a deterioration in the baby's condition, and how waiting can affect the mother to improve our knowledge of maternal role development for mothers of high risk infants.

APPENDIX: Sample Journal Pages

The first time to see my baby boy.

I have never seen nor imagined something that small and fragile. He had a feeding tube in his nose because he didn't know how to eat yet. and a little bit of oxygen and an I.V. and things in his navel. I just remember being scared still that he might not make it. The nurses in the NICU reassured me that he was tiny but mighty. The incubator he was in had a cute little blanket on top and his name all decorated for display.

Even though I was seeing him for the first time it felt like we had already met each other. I also noticed his giant feet which I can be certain are the exact replica of my own.

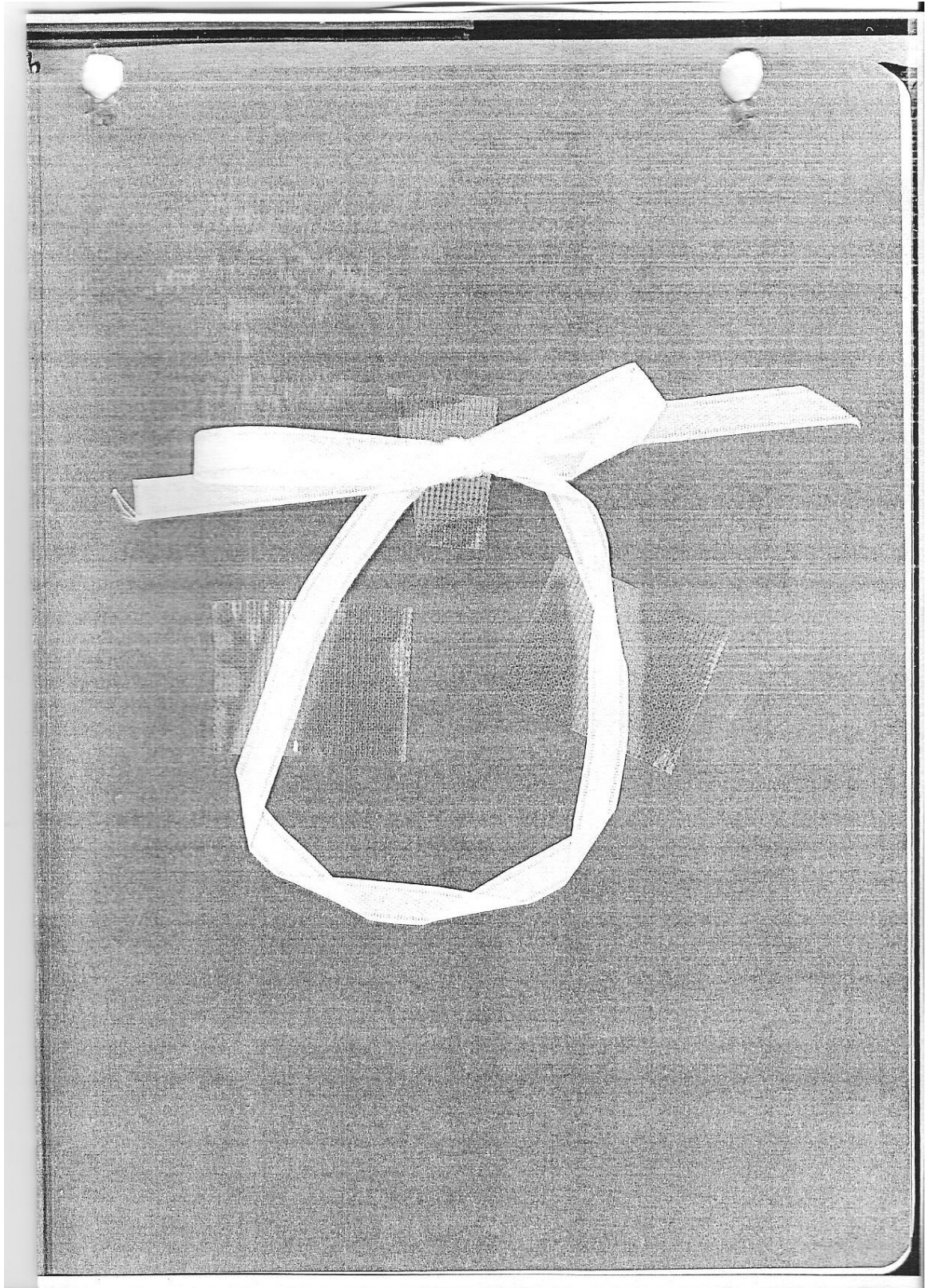
He was so beautiful. I don't really know how I expected his birth would be, but I never prepared for the idea that I wouldn't be able to

touch him, hold him, feed him, or even change him. all i could do Now was stare at him through his little box. The Nicu was wonderful the nurses all enjoyed there Job you could just see it in there faces. The younger nurses seemed to be excited everyday to brag on how well he was doing, after eight days in the Nicu he was Moved down a floor to the Nicu Nursery. I remember freaking out when I told the woman at the desk of the Nicu I was here to see my baby and she told me he wasnt there. I thought, ... what!!! ? And she explained to us that stable babies are moved to the Nicu nursery. The first time I saw him in the Nicu nursery the nurse asked if I'd like to change his diaper and I thought duh! I will never forget that Moment it was truly the first time I felt like I was getting to be his

cleaned up and handed to the mother. Having a preemie you never make it past that anticipation of the cry. Once ~~he~~ was here I wanted to hold him so bad & kiss him and welcoming him in this world but instead I barely caught a glance of him and then he was whisked off to the NICU. The time frame before you can see him again & seem longer than the pregnancy. You constantly praying and worrying is everything going to be okay; and it's hard to try to get some rest after delivery because the anticipation of wanting to actually see him & the stressing of him being okay you literally a nervous wreck. Then once he was here it was very intimidating to see him hooked up to all these monitors w/ the I.O's and in the incubator. He looked so fragile

like if you barely touch him he would  
break. For me this is where my emotional  
rollercoaster began. Once he was here  
outside the womb, you just wonder  
how in the world is going to develop  
outside the womb. Even though the  
Dr's + Nurses prepares you for the  
process ahead you never really  
know what to expect. I constantly  
wanted to stay by his bedside  
it seemed like to me if I was in  
his presence he wouldn't feel  
that motherbond you want to  
give him. For the three days I  
was in the hospital I was back  
and forth all day + night more  
so yearning for that intimate bond  
of a mother + child. I had almost  
like a emptiness to me or a feeling  
that was some how neglecting my  
child because I could hold him +  
when I could touch him.





## References

### Chapter One

- Bialoskurski, M., Cox, C. L., & Hayes, J. A. (1999). The nature of attachment in a neonatal intensive care unit. *Journal of Perinatal and Neonatal Nursing*, 13(1), 66-77.
- Black, B. P., Holditch-Davis, D., & Miles, M. S. (2009). Life course theory as a framework to examine becoming a mother of a medically fragile preterm infant. *Research in Nursing & Health*, 32, 38-49.
- Fenwick, J., Barclay, L., & Schmied, V. (2001). Struggling to mother: A consequence of inhibitive nursing interactions in the neonatal nursery. *Journal of Perinatal and Neonatal Nursing*, 15(2), 49-64.
- Fenwick, J., Barclay, L., & Schmied, V. (2008). Craving closeness: A grounded theory analysis of women's experiences of mothering in the special care nursery. *Women and Birth*, 21, 71-85.
- Flacking, R., Ewald, U., Nyqvist, K., & Starrin, B. (2006). Trustful bonds: A key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science & Medicine*, 62, 70-80.
- Heermann, J., Wilson, M., & Wilhelm, P. (2005). Mothers in the NICU: Outsider to partner. *Pediatric Nursing*, 31(3), 176-182.
- Hurst, I. (2001). Mothers' strategies to meet their needs in the newborn intensive care nursery. *Journal of Perinatal and Neonatal Nursing*, 15(2), 65-82.
- Johnson, A. (2007). The maternal experience of kangaroo holding. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing*, 36(6), 568-573.



- Lee, S.-N. C., Long, A., & Boore, J. (2009). Taiwanese women's experiences of becoming a mother to a very-low-birth-weight preterm infant: A grounded theory study. *International Journal of Nursing Studies*, 46, 326-336.
- MacDonald, M. (2007). Mothers of pre-term infants in neonate intensive care. *Early Childhood Development and Care*, 177(8), 821-838.
- Mercer, R. (1985). The process of maternal role attainment over the first year. *Nursing Research*, 34(4), 198-204.
- Mercer, R. (2004). Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship*, 36(3), 226-232.
- Roller, C. G. (2005). Getting to know you: Mothers' experiences of kangaroo care. *Journal of Obstetric, Gynecologic and Neonatal Nursing*, 34(2), 210-217.
- Rubin, R. (1976). Maternal tasks in pregnancy. *Journal of Advanced Nursing*, 1, 367-376.
- Shin, H., & White-Traut, R. (2007). The conceptual structure of transition to motherhood in the neonatal intensive care unit. *Journal of Advanced Nursing*, 58(1), 90-98.
- Wigert, H., Johansson, R., Berg, M., & Hellstrom, A. L. (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Sciences*, 20, 35-41.

## Chapter Two

- Armentrout, D. (2007). Holding a place: Parents' lives following removal of infant life support. *Newborn and Infant Nursing Reviews*, 7(1), e4-e11.
- Cescutti-Butler, L., & Galvin, K. (2003). Parents' perceptions of staff competency in a neonatal intensive care unit. *Journal of Clinical Nursing*, 12, 752-761.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through qualitative Analysis*: Sage Publications.
- Fenwick, J., Barclay, L., & Schmied, V. (2001). Struggling to mother: A consequence of inhibitive nursing interactions in the neonatal nursery. *Journal of Perinatal and Neonatal Nursing*, 15(2), 49-64.
- Fenwick, J., Barclay, L., & Schmied, V. (2008). Craving closeness: A grounded theory analysis of women's experiences of mothering in the Special Care Nursery. *Women and Birth*, 21, 71-85.
- Flacking, R., Ewald, U., Nyqvist, K., & Starrin, B. (2006). Trustful bonds: A key to "becoming a mother" and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science & Medicine*, 62, 70-80.
- Flacking, R., Ewald, U., & Starrin, B. (2007). "I wanted to do a good job": Experiences of 'becoming a mother' and breastfeeding in mothers of very preterm infants after discharge from a neonatal unit. *Social Science & Medicine*, 64, 2405-2416.
- Gibbins, S. A. M., & Chapman, J. S. (1996). Holding on: Parents' perceptions of premature infants' transfers. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 25(2), 147-153.

- Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory*. Hawthorne, NY: Aldine Publishing Company.
- Hallberg, L. R. M. (2006). The "core category" of grounded theory: Making constant comparisons. *International Journal of Qualitative Studies on Health and Well-being, 1*, 141-148.
- Heermann, J. A., Wilson, M. E., Wilhelm, P. A. (2005). Mothers in the NICU: Outsider to partner. *Pediatric Nursing, 31*(3), 176-200.
- Lee, S.-N. C., Long, A., & Boore, J. (2009). Taiwanese women's experiences of becoming a mother to a very-low-birth-weight preterm infant: A grounded theory study. *International Journal of Nursing Studies, 46*, 326-336.
- Miquel-Verges, F., Woods, S. L., Aucott, S. W., Boss, R. D., Sulpar, L. J., & Donohue, P. K. (2009). Prenatal consultation with a Neonatologist for congenital anomalies: Parental perceptions. *Pediatrics, 124*(4), e573-e579.
- Orapiriyakul, R., Jirapaet, V., & Rodcumdee, B. (2007). Struggling to get connected: The process of maternal attachment to the preterm infant in the neonatal intensive care unit. *Thai Journal of Nursing Research, 11*(4), 251-264.

### Chapter Three

- Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality and Quantity*, 36(4), 391-409.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. London: Sage Publications.
- Express Scribe (Version 5.45) [Computer software]. Canberra, Australia: NCH Software.
- Retrieved July 14, 2012. Available from <http://www.nch.com.au/scribe/>
- Feinberg, J. (2013). *Wordle - Beautiful Word Clouds*. Retrieved October 20, 2013, from <http://www.wordle.net>

## **Chapter Four**

Feinberg, J. (2013). *Wordle - Beautiful Word Clouds*. Retrieved October 20, 2013, from

<http://www.wordle.net>

## Chapter Five

Feinberg, J. (2013). *Wordle - Beautiful Word Clouds*. Retrieved October 20, 2013, from <http://www.wordle.net>

## Chapter Six

Feinberg, J. (2013). *Wordle - Beautiful Word Clouds*. Retrieved October 20, 2013, from <http://www.wordle.net>

## Chapter Seven

Feinberg, J. (2013). *Wordle - Beautiful Word Clouds*. Retrieved October 20, 2013, from <http://www.wordle.net>



## Chapter Eight

Feinberg, J. (2013). *Wordle - Beautiful Word Clouds*. Retrieved October 20, 2013, from

<http://www.wordle.net>

## Chapter Ten

- Bialoskurski, M., Cox, C. L., & Hayes, J. A. (1999). The nature of attachment in a neonatal intensive care unit. *Journal of Perinatal and Neonatal Nursing, 13*(1), 66-77.
- Charmaz, K. (2006). *Constructing Grounded Theory: A Practical Guide through qualitative Analysis*: Sage Publications.
- Fenwick, J., Barclay, L., & Schmied, V. (2001). Struggling to mother: A consequence of inhibitive nursing interactions in the neonatal nursery. *Journal of Perinatal and Neonatal Nursing, 15*(2), 49-64.
- Fenwick, J., Barclay, L., & Schmied, V. (2008). Craving closeness: A grounded theory analysis of women's experiences of mothering in the special care nursery. *Women and Birth, 21*, 71-85.
- Heermann, J., Wilson, M., & Wilhelm, P. (2005). Mothers in the NICU: Outsider to partner. *Pediatric Nursing, 31*(3), 176-182.
- Hurst, I. (2001). Mothers' strategies to meet their needs in the newborn intensive care nursery. *Journal of Perinatal and Neonatal Nursing, 15*(2), 65-82.
- Lee, S.-N. C., Long, A., & Boore, J. (2009). Taiwanese women's experiences of becoming a mother to a very-low-birth-weight preterm infant: A grounded theory study. *International Journal of Nursing Studies, 46*, 326-336.

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Isaacs, K. B., & Shreve, K., "Pain in the Neonate." *Neonatology: Management, Procedures, On-Call Problems, Diseases, and Drugs*. Ed. Tricia L. Gomella, M. Douglas Cunningham, and Fabien G. Eyal 7th ed. New York: McGraw-Hill Professional, 2013. 172-176. Print.

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