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## **Stories, Ethics and the Interpretation of Meaning: Bearing Witness to Mothers' Stories of Their Neonatal Intensive Care Unit Experience**

Angela Chisum Blackburn  
*University of Southern Mississippi*

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**The University of Southern Mississippi**

**STORIES, ETHICS AND THE INTERPRETATION OF MEANING: BEARING  
WITNESS TO MOTHERS' STORIES OF THEIR NEONATAL INTENSIVE CARE  
UNIT EXPERIENCE**

**by**

**Angela Chisum Blackburn**

**Abstract of a Dissertation  
Submitted to the Graduate Studies Office  
of The University of Southern Mississippi  
in Partial Fulfillment of the Requirements  
for the Degree of Doctor of Philosophy**

**May 2009**

## ABSTRACT

# STORIES, ETHICS AND THE INTERPRETATION OF MEANING: BEARING WITNESS TO MOTHERS' STORIES OF THEIR NEONATAL INTENSIVE CARE UNIT EXPERIENCE

by Angela Chisum Blackburn

May 2009

This study grounded in narrative perspectives was conducted to uncover mothers' experience of having a baby in the Neonatal Intensive Care Unit (NICU). The purpose of this study was to describe and interpret mothers NICU experiences, and to sensitize health care professionals about the importance of mothers' personal experience stories.

The NICU experience began with mothers' birth experience or the incident that led up to her infant requiring care in the NICU and her experience extended beyond the NICU with future concerns about the health and wellbeing of her baby.

Stories of mothers' experience were gleaned from data generated from audio-taped interviews, photographs taken by families, mothers' journals and mothers' NICU memorabilia. Four mothers participated in the study and their interviews were transcribed verbatim and provided the primary text for analysis. Watson's (1985) carative factors provided a theoretical structure for studying and understanding mother's stories. Accordingly, narratives provided a tentative foundation for caring in nursing. Looking at narratives with carative factors in

mind helped to delineate them and their importance in helping a nurse to care for another person.

Data analysis was guided by narrative inquiry combining structural approaches of Labov and Waletzky (1967/1997), and Riessman (2008), adapted from Gee (2005). Analysis also identified narrative features and transcendent themes drawing on approaches outlined by Charon (2006).

The first level of reflection identified three core narratives: enchantment, disenchantment and re-enchantment stories. Enchantment stories were stories mothers told about their hopes, dreams and ideals for their first pregnancy, birth and baby. Disenchantment stories were stories that mothers told when things didn't go as planned and babies required care in the NICU. Re-enchantment stories were stories told by mothers about their attempts to create normalcy in the chaos of the NICU. These stories are also about mothers' efforts to create new ideals, hopes and dreams as they create memorable moments and celebrate each new milestone.

The second level of reflection revealed descriptions of five narrative features and transcendent themes. The first narrative feature of *causality/contingency* illuminated the following themes: *tears in the fabric of daily life, mourning life as imagined, questions of why? and search for answers*. The second narrative feature of *temporality* illustrated the following themes: *rollercoaster, waiting, baby jail or petting zoo?* The third narrative feature of *singularity* identified the following five themes: *tailored care, assembly line, desire for normality, burden of depression and prior experience with illness and death*.

The fourth narrative feature of *intersubjectivity* gleaned the subsequent themes: *encounters with others, earned trust, butterflies and curtains, protecting family and family support*. The fifth narrative feature of *ethicality*, revealed the following transcendent themes: *valued responsiveness, vulnerable aspects of life, demonstrating hope and faith and desire to help others*.

This research makes a case to health care providers that through narrative understanding, we can maintain a better balance between the highly technological nature of the NICU and also achieve therapeutic relationships with patients by embracing our duties toward individuals. Mothers' stories have the potential to provide moral education, reminding care providers who NICU mothers are, what concerns them and why certain care practices are valuable. These care practices can help guide care providers in what to do next and how to live now. Through narrative understandings, mothers' stories can help sort out what makes some care practices better than others. Implication for health care professionals in practice, education, healthcare policy and research are described.

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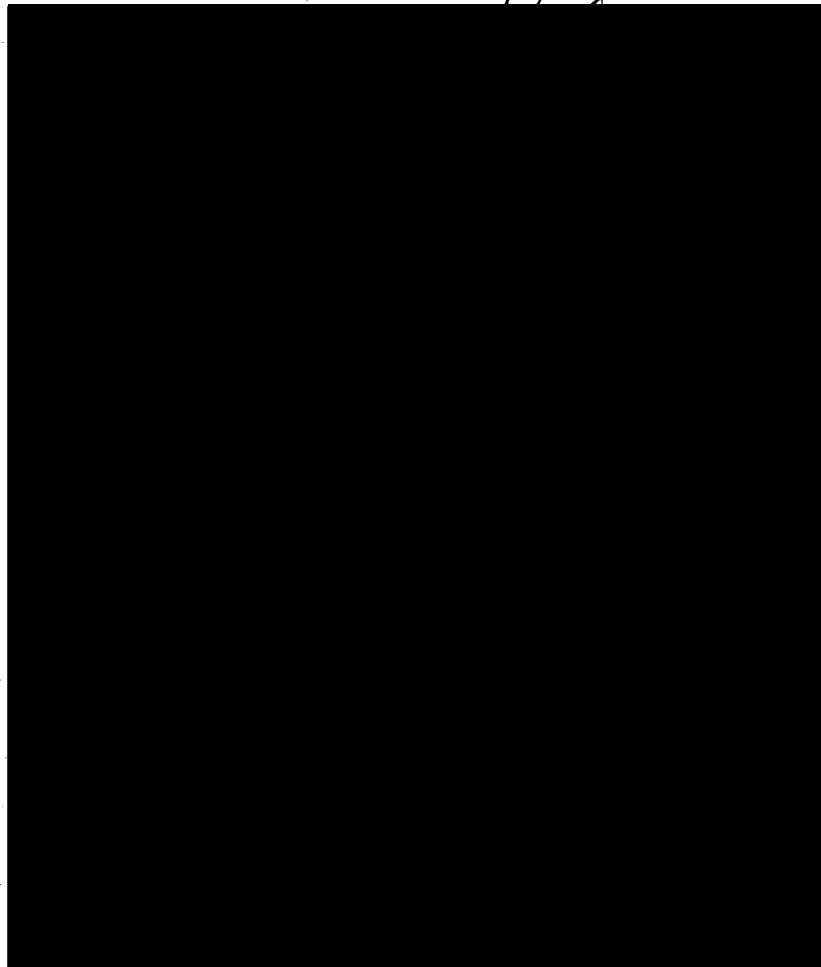
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**Approved:**



**May 2009**

**DEDICATION**

*To my mother, Mamie Chisum,  
who joins me in remembering my father*

**ROY PARKER CHISUM**

**1942-2004**



## ACKNOWLEDGEMENTS

Many colleagues, friends and relatives have been instrumental in assisting me in this research study. I wish to acknowledge these persons who have shared their thoughts, ideas and insights with me throughout the years.

First, to the following faculty members at The University of Southern Mississippi: To my closest advisor and friend, Major Professor Dr. Karen Saucier Lundy, who helped me to embark on my first qualitative research experience, always there to keep me on track and guide me with her knowledge and expertise. The completion of my doctoral work and dissertation could not have happened without the involvement, guidance, and intellectual vision of Professors Sherry Hartman, Bonnie Harbaugh, Susan Mayfield-Johnson, Sarah (Selen) Lauterbach and Amy Chasteen Miller. I am also appreciative of the care and attention given to me by Rebekah Young, transcriber.

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Next, I wish to thank the four women who willingly invited me into their lives; sharing stories on this sensitive and deeply emotional experience. Without their genuine interests, commitment and dedication and their willingness to share this study would not have been possible. It is an incredible honor and privilege to learn from you.

And finally, I want to acknowledge the powerful impact that my family has had on my thinking. I am fortunate that I was blessed with two loving and nurturing parents. To my mother Mamie, who always inspired me and provided me with emotional support needed to carry on, and my late father Roy Chisum who stimulated my love of books, reading and learning. I wish to thank my step-children and grandchildren who have cheered me on and provided love and laughs. I would also like to express my gratitude and heartfelt thanks to my husband and closest friend, Mike Blackburn, who listened patiently, commented constructively, and never stopped believing in me. I am eternally grateful for your love and friendship in my life.

My movement in this journey has been painstakingly slow and tedious. I am grateful to all of you for the support and sacrifices made to assist me with achieving this goal and for each of you allowing me the time that I needed to complete this project.

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## CHAPTER I

### INTRODUCTION

**"We must be present with ourselves, in the moment, and mindful of the ease with which we turn away, get distracted, and forget what's important. We can drift along, and most of us do, moving from project to project, keeping questions of ultimate significance at a distance." (Freeman, 1997)**

#### **Narrative Beginnings/Situating Self in the Study**

In this chapter I will present the story that led to my interest in this study, situate the inquiry within the Neonatal Intensive Care Unit (NICU) environment, and provide justification for focusing on personal narratives told by mothers who have experienced having an infant in the NICU. I will also explain the importance of understanding how women construct stories and find meaning in experience and make sense out of the everyday world in which they find themselves. Finally, I will outline the nursing scholars that were influential to the study.

The three specific aims of this study are: (1) To describe stories of mothers' NICU experiences, (2) to describe the meaning in stories, and (3) to illuminate ethical concerns embedded in mothers' stories and their potential impact on healthcare. Ethical concerns tell us how women with ill infants story "ethics of everyday life" and/or judges and understands their lived experiences against the ethical, emotional, practical and fateful demands of life as they have come to understand them (Jackson, 1989).

#### *Jon Jon's Story*

This research interest started several years ago with a conversation I had with a mother in the NICU. We were discussing a poem that was hanging on her baby's crib. I was interested in finding out how mothers find meaning in the NICU experience through art, poetry, journaling, memorabilia etc. As our conversation



progressed, I learned that this mother had received a mistaken prenatal diagnosis of Thanatophoric dwarfism (the most common form of lethal neonatal dwarfism), and how it changed her entire pregnancy. She told me how the diagnosis made her feel saddened throughout her pregnancy, and therefore she was not able to enjoy the excitement of giving birth; she only mourned what could have been. When she delivered a normal, healthy baby only a few weeks prematurely, she could not fully enjoy the experience because she was frustrated at how badly things had gone prenatally. From my vantage point as a neonatal nurse practitioner, the poem hanging in her baby's crib was a representation of her anticipated loss and faith, an experience not easily verbalized with healthcare professionals responsible for the (mis)diagnosis.

*Jon Jon*

Jon Jon  
 So light and so fair,  
 A miracle at conception  
 With so much love to bear.  
 But God brought you forth,  
 As a tiny little man,  
 So you will serve the Great I am.  
 With your parents faith and so many prayers,  
 You proved the Doctors wrong with Gods loving care.  
 He placed you in your parent's hands,  
 And because of your miracle birth  
 Your testimony still fills America's land.  
 As you grow your family will see,  
 You're a miracle child, God's promised seed.

The poem illustrates emotional devastation and psychological turmoil that mothers often endure following antenatal diagnosis or (mis)diagnosis of actual or potential fetal abnormalities. The poem also demonstrates this family's strong religious faith and reliance on their faith to get them through this difficult ordeal.

The story also attests to the long lasting impact of such a scenario. Fortunately, for this mother, the misdiagnosis had a happy ending, but what of those parents who have a baby with a serious abnormality?

### *Faith's Story*

Next, is another poem that a mother shared with me, written by Faith's grandpa (Opa). Faith was born with a large encephalocele and after weeks in the NICU, she went home with her parents.

### **A Baby Named Faith**

Deep in the mythical darkness of conception,  
 life moved into the shape of an infant.  
 The Master was at work in hidden Majesty!  
 Life inside the womb was about to change life outside the womb.  
 Unknown, unseen, and unheard, her presence was beyond doubt.  
 She was life unexpected, unpredicted, and wonderfully made.

She cannot live was the declaration of knowledge and science.  
 Plan for depths of heartache was their warning.  
 She moved, she kicked, she waved her hand.  
 How could this life be cut short, be forbidden a chance?  
 She could not be like other babies, but she would not be denied.

Like a silent breath of air she moved into our world.  
 She breathed, she moved, she amazed us all.  
 With much difficulty she fights the odds for life.  
 With incredible determination she climbs her mountains.  
 One day, two days, now three; how can this possibly be?  
 She draws the attention of her new-found world.  
 She inspires the hope upon which miracles are built.  
 How long will this last? How much more can she do?  
 We hang in the balance, both me and you.  
 She holds us mesmerized before God's miracle of life.  
 So little, yet so strong; so small, yet, so beautiful;  
 She takes us to another level of radiance.  
 She carries us to a new dimension of existence.

We are not the same since this little one came.  
 She continues to teach us what life is about.  
 Life is love, kisses, cooing, and touch.  
 Life is movement, affection, and presence.  
 Life is a miracle, a marvel, and a Grace.

Life is a difference made by a baby named Faith.

----Her Loving Opa

The poem, *Baby Named Faith*, reflects the love and support that this devoted family had for Faith despite the uncertainties that go along with her diagnosis. The family had devoted themselves exhaustively to the well-being of this child, and the poem tells a story that involved an imaginary journey into their world. The poem communicates what is significant in their lives, how things matter to them and that despite uncertainties and the lack of a clear ending there is one thing that is certain. In spite of the tragedy of disability, Faith's story was about love, commitment, and courage. It was a story of living in the shadow of uncertainty, growing as individuals, and becoming closer with the ones they love. Sadly, Faith died in the loving arms of her mother while this paper was in its early stages she was two and half years old.

### *Kim's Story*

While talking with some of the mothers in the NICU, I noticed Kim, a new nurse in our unit, sitting nearby feeding a baby. She had been listening to our conversation about the poem and later offered to share her own story with me.

Later that day I talked briefly with Kim, and she offered to let me read a journal that she had kept during her NICU experience about her baby daughter Kristina. Later, while doing a project for a class that I was taking, I asked Kim if she would like to participate in an oral history interview, Kim accepted and told me the following story:

In 1991, Kim experienced depression following the death of her nine and a half month old first born child, Deana, to sudden infant death syndrome (SIDS).

About a year later Kim gave birth to Deandra, a healthy, full term baby girl. Deandra did not have any health problems and at the time of our interview Deandra was 10 years old and doing well.

Kim also suffered a second bout of depression following the premature birth of her third baby Kristina (the baby Kim had journaled about) who was born at twenty-four weeks gestational age (a full term pregnancy is 38-40 weeks gestation). Kristina required care in the NICU for about three months prior to her discharge. She was discharged on a home apnea (not breathing for >15-20sec.) and bradycardia (heart rate < 100) monitor for continuous monitoring at home. Kim learned cardiopulmonary resuscitation (CPR) so that she would be prepared to intervene should Kristina have an apnea and bradycardia episode (A & B episode/arresting episode) at home.

Kristina was an irritable infant who often cried and didn't sleep well, which is very common in premature infants. Kim experienced exhaustion and deep depression during the months following Kristina's homecoming. She experienced thoughts of harming herself and Kristina, but managed not to act on these threats by taking long walks with Kristina in her stroller. Kim knew something was wrong. She had always wanted to be a good mother and she didn't understand where these "terrible" thoughts about motherhood were coming from.

Kim's husband was on military deployment at the time and was only allowed infrequent short visits home, so he was not available to lend support or provide respite from the responsibilities of child care. Kim would also attempt to seek help from family and friends just to get an hour or so reprieve from Kristina's crying. However, few people would offer this assistance, as they didn't know how

to handle a crying premature baby. When there was no one to give Kim a break from the crying, she would get away for a few moments by having her breakfast in the garage. This as she explained, was a place not far from her crying daughter that allowed her to eat in peace.

Kristina required frequent follow-up appointments with her pediatrician. According to Kim, none of the physicians or nurses ever asked how she as a mother of a premature infant was doing. Kim was too afraid to mention the subject herself. The focus was on the baby and it seemed to Kim that an effort was being made to rush them out of the office due to her baby's constant crying. After months of sleepless nights, Kristina slowly improved. Her apnea and bradycardia monitor was discontinued and she began to sleep through the night. Just about the time Kim was feeling better, she found out that she was pregnant with her fourth baby, Shawn.

Kim was excited, yet scared, by the news of her pregnancy. She was excited that she and her husband would be having a baby boy, but frightened that the depression would return. Kim took it easy and did everything she could to carry her pregnancy to full term. However, Kim's pregnancy was interrupted when her baby boy was born prematurely at 24 weeks gestational age and after a short time in the NICU, Shawn died in Kim's arms, surrounded by family.

In my interview, Kim gave a vivid account of her desire to be a good mother and she described how depression took hold of her life following the death of Deana. She also shared in detail how her depression continued through subsequent pregnancies. Her story also revealed the fear that social stigma places on women with depression and how it impedes the search for help and

understanding. Kim also feared that her family would fall apart, her child would be taken, she would be put into a psychiatric hospital and that she would embarrass her military husband, all of which would destroy the family life that she had imagined for herself.

Kim's story brought to light her struggle with depression following both infant loss and premature birth, a common experience among women who have suffered previous infant loss and premature delivery. Postpartum depression resulted from a chemical imbalance that was exacerbated by the experience of loss and subsequent pregnancy.

Her story exposed notions of honor and shame, and opened my eyes to the importance of bearing witness to mothers' personal stories in the NICU. Bearing witness in clinical practice is defined by Charon (2006), as a "committed active, respectful, confirming listening" (p. 180) to patient's self narratives. Kim's story also illuminated just how important it is for healthcare providers to not only seek out the stories but also to better understand their counterpart, silence.

Wilkan (2000) noted that narratives are not an option for many people such as Kim, in their most trying life circumstances. According to Wilkan, "everyday life, with its ordinary pot of trials and tribulations, often does not allow for or offer the consolation of letting words take flight thus to share one's burden with another" (p. 232). The connection is twofold according to Wilkan (2000) "Silence breeds pain, and pain nurtures silence" (p. 233). Lauterbach (2003) explored the phenomenological silence that surrounds infant death and noted that phenomenological silence involves a lack of social awareness and consciousness, as being related to denial. Lauterbach (2003) also noted that

“people who live *with* difficult and painful experiences are often silent and are silenced. They often do not want to worry or bother others and are ‘hushed’ if they break the silence” (p. 38).

So it was with Kim. She was silent about her experiences with post partum depression so that she could protect and honor her military husband, because of the shame she feared would befall her family and perhaps for other untold reasons. Her silence intensified her pain and that pain nurtured further silence. Kim’s experience had an isolating effect, like that described by Lauterbach (2003). Few opportunities existed for Kim to process the experience with even the most intimate and close relationships. Kim isolated herself and those close to her isolated themselves. Wilkan (2000) and Lauterbach (2003) do not advocate imposition or intrusion by practitioners or researchers into the lives of their participants but a sharper exploration of the counterplay between silence and narrative as a way to enhance our understanding of lived predicaments. To understand lived experience, Wilkan (2000) noted that “ we need narratives, stories of unfinished, muddled, in-the-midst-of experiences whose only certainties are the beginnings or turning points... And we need stories/narratives of experiences groping for meaning, whose onset as well as ending line are in the blue” (p. 234).

As I reflected more on the stories of mothers in my clinical practice as a neonatal nurse practitioner, I began to formulate the following questions: What can nurses learn from the stories told by mothers who have had the experience of having a baby in the NICU? What do the stories reveal about the mothers’ search for meaning? What ethical concerns are represented and constructed in

the stories told by mothers? What does the interplay between silence and narrative have to teach us and how does a better understanding of this interplay enhance our understanding of lived predicaments? How might mothers' stories help shape the practices of nurses and other healthcare providers in ways respectful of the meanings, obstacles, contradictions, options and possibilities that their stories disclose? And finally, how might these findings promote dialogue among nurses and other healthcare providers in order to preserve and extend responsiveness, care, comfort, safety, hope and opportunity for mothers and ill infants within and beyond the NICU?

Following my interview with Kim, I began to contemplate how often healthcare professionals, especially nurses and physicians fail to understand the importance of our patients' stories and their silences and how understanding is critical in providing sensitive, relevant and appropriate care. After bearing witness to Kim's story and dwelling on the narratives told to me by other mothers' in my practice, I began to question how women make narrative sense of their experiences, particularly their moral and existential concerns.

After reading about narrative inquiry, which is defined as the study of experience as expressed in lived and told stories (Clandinin & Connelly, 2000). I began to ponder the moral importance of bearing witness to mothers' stories and wondered why many health professionals fail their patients when it comes to acknowledging and responding to their personal stories. Are we as nurses turning a deaf ear to the concerns of mothers as they attempt to make sense of and find meaning in their health/illness experience through storytelling? Are we



as nurses missing opportunities to make meaningful contributions in the improvement of patient care?

I do not believe the goal of nursing is to leave people to suffer alone, in silence, confusion and fear, but rather to promote healing, and to provide support to marginalized individuals. Following my discussions with these mothers in the NICU, it became clear to me that esthetic forms including narrative, poetry, journaling, photography, memory books, etc. offer a richly textured, insightful, and complex means by which to make sense of their world and that the nursing community will greatly benefit from scholarship that brings this to light.

The research questions I was considering lend themselves to qualitative methods. In order to navigate esthetic forms, I began to explore alternatives to more traditional research (Creswell, 2007; Munhall, 2007; Sandelowski 1991, 1994, 2004), and have found that narrative inquiry is a powerful tool in that it makes issues of concern to the NICU mother infinitely more salient by expressing thoroughly the effects they have on the human condition. I am moved to conduct this present research because I am concerned that we have an under-articulated sense of the value of mothers' narratives as well as their silences in the clinical practice setting.

Therefore, in this study, I wanted to learn more about the expressed reality of the experiences of the women that I encountered in everyday practice, about their suffering, their joy and their perseverance, and the way they construct stories to make moral sense of their experiences. Kleinman (2006) noted that "living a life embraces both positive and negative conditions and indeed is a story about how the two come together" (p. 14). Kleinman continues, "Enlightenment

about genuine reality should not demoralize us; it gives meaning to our small triumphs and daily pleasures" (p. 14).

When I heard about mothers' struggles with adversity, the heartbreaking feelings of stigma and marginalization, the desire for self-expression, the urge to speak to and assist a community of fellow sufferers, I saw the critical need to validate and facilitate this process. Failure to bring their stories to light would invalidate the existential struggles for meaning that this process represents; those who care for them and their children are missing what mothers' have to teach us.

### Context of the Study

The setting of my research will revolve around the NICU experience. A major challenge facing healthcare providers within the NICU is to combine advanced technological care for premature and ill infants with a sensitive and individual approach to the needs of mothers' and families. Of the nearly 4 million live births annually in the United States, more than 500,000 infants, or approximately 12.7%, are born at less than 37 weeks gestational age. Birth of very premature infants (less than 32 weeks gestation) makes up approximately 2.03% of all live births (Martin et al., 2007).

Prematurity is the leading cause of infant death in the first month of life. Although advances in medical technologies and therapeutic perinatal and neonatal care have led to improved rates of survival among premature babies, surviving infants have a higher risk of morbidity. The highest mortality and morbidity rates occur in babies born very early and very small. They are at highest risk for a number of serious complications including but not limited to:

infection, respiratory distress syndrome (RDS), intraventricular hemorrhage (IVH), chronic lung disease (CLD), retinopathy of prematurity (ROP) and other visual problems contributing to blindness, cerebral palsy (CP), language and developmental delays ("Premature labor and birth" section, NICHD web site, 2007).

Premature infants however, are not the only babies to require care in the NICU. Near term or full-term babies may be affected by a host of maternal medical conditions, for example, maternal diabetes, pregnancy induced hypertension (PIH) and pre-eclampsia. Full-term infants may also require care in the NICU due to Persistent Pulmonary Hypertension of the Newborn (PPHN) which occurs when the transition of the pulmonary circulation at birth does not proceed normally. Other babies are admitted to the NICU due to birth injuries which are defined as "injuries sustained during the birth process, which includes labor and delivery. These injuries may be unavoidable and occur despite skilled and competent obstetric care, as in an especially hard or prolonged labor or with an abnormal presentation" (Mangurten, 1997, p. 425).

Babies also enter the NICU because they have congenital anomalies or birth defects. Birth defects have been described as abnormalities of structure, function or metabolism (body chemistry) present at birth that results in physical or mental disabilities, or death. Birth defects are the number one cause of infant death in the United States. In the U. S., about 3% of babies are born with birth defects each year. Birth defects account for nearly 20% of infant deaths in the United States ("Birth defects" section, CDC web site, 2008).

Kendall-Tackett (2005), explored sources of trauma for women associated with perinatal events including birth experience, prematurity, and childbearing loss; she found that premature birth is a source of trauma for women (Kendall-Tackett, 2005). The birth of an ill or prematurely born infant has been characterized as an "ambiguous loss," in that parents often feel the contradictory emotions of joy at the babies' birth, and grief over their fragile state. In a qualitative study of family members who experienced a premature delivery, the subjects experienced a range of reactions. They mourned the loss of a healthy full-term pregnancy and feared for the baby's life and health. They often had difficulty communicating their grief to others, because the baby was still alive (Golish & Powell, 2003).

In his most important work, *Being and Time* (1962), the existential philosopher Heidegger developed his concept of *angst* (a kind of intense anxiety and dread) to characterize the feeling and experience of disintegration that can result from seriously traumatizing events such as bereavement and other forms of loss, such as relationship breakdown, illness, and depression. For mothers, giving birth prematurely or giving birth to an ill infant requiring care in the NICU, their experience can represent a traumatic event in that it can create angst for the mother.

When mothers experience premature labor and delivery or the birth of an ill infant, they are suddenly face-to-face with the fundamental precariousness of existence. Angst highlights the way in which we routinely take for granted our sense of implicit connection between events, people, plans, aims, objectives, values and beliefs. When one element disappears, the whole complex

configuration of plans, hopes and assumptions are suddenly shattered (Crossley, 2000, pp. 56-57). Frank (1995) characterizes such experiences as "narrative wreckage" (p. 53). "The story is wrecked because its present is not what the past was supposed to lead up to, and the future is scarcely thinkable" (p. 55)

Perhaps the use of the metaphor of a traveler in a foreign land will serve to describe entry into the NICU landscape. Survival in this strange terrain requires much from the traveler: a new map for understanding and navigating the landscape, and a guidebook for interpreting the foreign language. Within the unexplored territory, visions of physical and psychic suffering are apparent and constant. The presence of vulnerability, uncertainty and despair are constant reminders of the fragility of life in the NICU. There is no quick escape, for most, from this strange land. Many travelers will tread here for days to months and some will remain for up to a year. The destination and its path are now suddenly different from what the traveler had initially imagined. Most devastating for the traveler of this strange land, perhaps, is the inability to continue to envision what is good for oneself and one's newborn baby and to determine how to achieve this end.

The search to examine the series of separate events that led up to the wrecked story, and the quest to discern the states of affairs that have taken place since one's arrival, and the desire to understand what the future entails is a personal process that occurs over time. NICU mothers are forever transformed by their experiences. This transformation is expressed not only in personal narratives but also through a variety of esthetic forms including artifacts such as journals, photographs, poetry, memory books, art, metaphor etc. All have the

potential to lead to a fuller understanding of mothers' NICU experiences (Clandinin, 2007; Denzin, 1989; Riessman, 1993, 2008).

### Narrative Truth

Truth in scientific explanation aims at objectivity through rigorous and systemic data collection procedures whose properties are determined through measurement and experimentation (empiricism). However, Josselson and Lieblich (1999) emphasized that "narrative research is a meaning-making endeavor with multiple truths" (p. xi). As Brunner wrote, "With science, we ask for some verification (or proof against falsification). In the domain of narrative... we ask instead that, upon reflection, the account correspond to some perspective we can imagine or 'feel' as right" (Brunner, 1986a, pp. 51-52).

In qualitative research, with its emphasis on the "the narrative turn" (Bochner, 2001), truth is judged differently than in a quantitative inquiry. "A story is fictional not in virtue of its content being false, but in virtue of its being narrated and read or heard, as part of a practice of a special sort" (Goldie, 2004 p. 161). In other words, stories are representations of a life experience as opposed to the life itself. Stories reconstruct lives in every act of the telling. Patton (2002) explains, that "stories are usually constructed around a core of facts or life events, yet allow a wide periphery for freedom of individuality and creativity in selection, addition to, emphasis on, and interpretation of these remembered facts" (p. 551). Stories are more about meaning than truth, "the making out of what happened and the making up of what something means" (Sandelowski, 1991, p. 165).

The power of stories is that they attempt to capture the individual's point of view, examining the constraints of everyday life by securing rich descriptions of experience (Denzin & Lincoln, 2003). As such, their truth is judged by artistic criteria with a focus on aesthetics, creativity, interpretive vitality, and expressive voice. The aim of narrative inquiry is to engage those receiving the work, to connect with them, to move them, to provoke and stimulate reflection. According to Patton (2002) "artistic expressions of qualitative analysis strive to provide an experience with the findings where "truth" or "reality" is understood to have a *feeling dimension* that is every bit as important as the cognitive dimension" (p. 548).

Denzin (1989) established the following points in regards to narrative truth: (1) stories always come in multiple versions, and they never have clear endings or beginnings; (2) stories are grounded in a group's culture where criteria of truthfulness are established; (3) the stories told are never the same as the stories heard; (4) stories are shaped by larger ideological forces which put pressure on persons to establish their individuality (and self control) in the stories they construct (p. 77). Different perspectives about such things as truth and the nature of reality constitute paradigms or world views based on alternative epistemologies and ontologies and are often the subject of heated debate within nursing.

### Paradigm Conversations in Nursing

Conversations about epistemological paradigms and the nature of "reality" and knowledge are long-standing in nursing. Patton (2002) defined paradigm as: "A worldview, a general perspective, a way of breaking down the complexity of

the real world. As such paradigms are deeply embedded in the socialization of adherents and practitioners; paradigms tell them what is important, legitimate and reasonable.” (p. 69). An important aspect of the nursing paradigm debate involves the question of whether nursing is a science, an art, both or neither.

Traditionally, nursing has aligned itself with the medical sciences and its research agenda, applying natural science methods in the study of persons and health issues. This led to a perceptual shift toward the science of nursing (empirics). In that paradigm humans are studied objectively with the goal of intervention and prediction.

More recently, in a move to claim closer identify with the human sciences, different methods of inquiry have been endorsed, which are primarily qualitative (Chinn & Watson, 1994; Munhall, 2007). Those in nursing using human science methods have moved from the reductionist approach of the natural sciences to one that recognizes the wholeness and uniqueness of individual experience and constructed meanings in context-specific settings. Methods in this paradigm focus inquiry on interpretation, meanings of experience, and understanding rather than causal explanations.

Watson (1985) encouraged the nursing profession to develop a science of caring for nursing practice and she offered ten carative factors that form a structure for studying and understanding nursing as the science of caring (Watson, 1985, p. 9). Watson’s (1985) carative factors provided a theoretical structure for studying and understanding mothers’ stories in this study (see Table 1).



Table 1.

## Watson's Ten Carative Factors

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*Watson's Ten Carative Factors*

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1. The formation of a humanistic-altruistic system of values
2. The instillation of faith-hope
3. The cultivation of sensitivity to one's self and to others
4. The development of a helping-trust relationship
5. The promotion and acceptance of the expression of positive and negative feelings
6. The systematic use of the scientific problem-solving method for decision making
7. The promotion of interpersonal teaching-learning
8. The provision for a supportive, protective, and (or) corrective mental, physical, sociocultural, and spiritual environment
9. Assistance with the gratification of human needs
10. The allowance for existential-phenomenological forces

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*Watson (1985) Nursing and the Philosophy and Science of Caring.*

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Accordingly, narratives provided a tentative foundation for caring in nursing. Looking at narratives with carative factors in mind helped to delineate them and their importance in helping a nurse to care for another person.

Balancing science with humanism requires that nurses view nursing research through a different lens. Rather than a dichotomy, nursing research should be

viewed as a cyclical continuum that finds its origins in qualitative research and its validation in quantitative research (Chinn & Watson, 1994; Munhall, 2007).

As the non-foundational paradigm, a postmodern turn would allow the qualitative research interview to be seen as a construction site of knowledge, thus allowing all sorts of evidence to contribute to the richness of our comprehension and our ability to make sense of the world around us (Kvale, 1996). The most important point in this paradigm shift according to Patton (2002) is to judge the quality of a study by its intended purposes, available resources, procedures followed, and results obtained all within a particular context and for a specific audience (pp. 71-72).

Given the above point, paradigms are important theoretical constructs for illuminating fundamental assumptions about the nature of reality and therefore should provide a range of possibilities when selecting methods. The point, according to Patton (2002) is to do what makes sense, report fully on what was done, and what the implications are for findings (p. 72).

Richardson (2003) author of *Writing: A method of inquiry*, asserts that the central image for qualitative inquiry is the crystal not the triangle. She noted that traditionally in staged research triangulation is supported, which is the researcher's use of different methods such as interviews, census data, and documents to validate findings. She continued that these methods carry the same domain assumptions, including the assumption that there is a "fixed point" or "object" that can be triangulated. But in postmodernist mixed-genre texts, we do not triangulate; we *crystallize*.

Richardson (2003) offered a new lens from which to view qualitative research design. Richardson elegantly explains the concept of crystallization as part of the postmodern project. Crystallization recognizes the many facets of any given approach to the social world as a fact of life. The image of the crystal “combines symmetry and substance with an infinite variety of shapes, substances, transmutations, multidimensionalities, and angles of approach. Crystals grow, change, and alter but are not amorphous” (Richardson, 2003, p. 517). What we see when we view a crystal, for example, depends on how we view it, how we hold it up to the light or not. Richardson continues, “Crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic. Paradoxically, we know more and doubt what we know” (p. 518).

Crystallization in nursing research, then incorporates the use of other disciplines such as art, sociology, history, dance, architecture, and anthropology to enlighten our research process and broaden our understanding of method and substance. Benner, Tanner and Chesla (1996) supported and exemplified this approach to nursing research. They utilized multiple sources of text in their studies articulating the nature of clinical and ethical expertise in nursing, including narrative accounts to gain access to the participants' ways of understanding and structuring their experiences. They also used photography as a source of visual text to disclose aspect of the situation that may be overlooked or unattended to by the participants. Benner (1994) explained that photographic essays of experience can give access to participants' concerns and feelings that may not show up in conversation. Benner (1994) also maintains that films,

novels, poetry, art, videotape, news clips, written documents and first person accounts can be rich sources of textual data (p. 119).

Chinn and Watson (1994) have also examined nursing esthetics and noted that "the art of nursing is the capacity of a human being to receive another human being's expression of feelings and to experience those feelings for oneself. The artistic expression of nursing according to Chinn and Watson (1994) includes intentional auditory, visual, sensory, olfactory, and tactile art or acts. Watson (1988), claimed that nursing art is lived, expressed and cocreated in the caring moment. Cultivating a respect for narratives and esthetic modes of expression in clinical practice has the potential to offer opportunities for caring moments to take place, particularly in the highly technological and medically specialized environment of the NICU.

In the current study, multiple data sources and contexts are preferable in order to create a more naturalistic account and to prevent an overly narrow empirical perspective. I have come to understand that sensitive experiences are best captured by qualitative methodologies. Reinharz (1992), echoed this belief, she has noted that to understand our psychological and social lives, an empathetic understanding is needed and that this cannot be achieved fully via the detached objectivity of the scientific experimental method. Qualitative researchers use natural settings and a host of different ways "that describe routine and problematic moments and meanings in individual lives" (Denzin & Lincoln, 1994, p. 2).

I believe that both methods of research, experimental (quantitative) and naturalistic (qualitative), are essential to the nursing professions repertoire of

knowledge. For this study however, I have made the decision to represent participant mothers' accounts qualitatively through their narratives, photographs and journal entries shared with me in interviews. Robinson and Hawpe (1986) addressed these contrasting strategies:

Human beings are curiously ambivalent about generalizations. On the one hand, we try to assimilate the diversity of daily life to a catalogue of maxims and rules of thumb. On the other hand, we emphasize the particularity of each case. We are most comfortable it seems with a point of view based on degrees of resemblance between things or between events. As noted earlier, narrative is a cognitively efficient compromise between uniqueness and universality because stories are contextualized accounts, they convey the particularity of any episode. And because they are built upon a generic set of categories and relationships each story resembles other stories to varying degrees. A sense of familiarity is the result of this underlying similarity. (p. 118)

#### Theoretical Influences in Nursing

Many nursing theorists, philosophers and researchers were influential in the organization of this study: Benner (1991, 1994); Benner, Tanner, & Chesla (1996); Carper (1978); Munhall (1994, 2007); Sandelowski (1991, 1994, 2004); Watson (1985, 1999, 2005).

I began to study Carper's *Fundamental Patterns of Knowing in Nursing* (1978) when I was in graduate school. As a neonatal nurse practitioner student I was required to keep a journal classifying my reflections according to the four fundamental patterns of knowing described by Carper as *empirics* (the science of

nursing), *esthetics* (the art of nursing), *ethics* (the moral component of knowing) and *personal knowing* (private knowledge). It was then that I learned that no single pattern of knowing is superior to another. Empirics may not always offer the answers to practice situations; there are other patterns of knowing that can provide insight and understanding to assist in decision-making, implementation and acceptance. Building on her conceptualization, Chinn and Kramer (1994) outlined methods for developing each pattern of knowing in nursing, and for expressing or communicating that which is known. Each pattern of knowing is viewed as equally necessary, with each pattern contributing an essential component of what is required for the discipline and practice of nursing. Together (Carper, 1978; Chinn & Kramer, 1994) provided the basis for examining the development of comprehensive knowledge in nursing.

After several years in clinical practice, I was offered the opportunity to teach neonatal nurse practitioner students. My role was to focus on the students' experiences during clinical practice and once again I was face-to-face with Carper's patterns of knowing. Only this time, while reading student's journals of their clinical experiences, I noticed how easy it was for students to write about nursing science and evidence-based practice. However, students had significant difficulty writing about or identifying aspects of personal, esthetic, and ethical ways of knowing from their clinical practice.

This realization contributed to the conceptualization of my study. I began to think that narrative inquiry engenders a means by which to understand and make sense of the world of NICU mothers, a world not easily articulated through traditional research practices. I also began to explore how such alternative

research approaches might serve nursing students in their understanding of the fundamental patterns of knowing, emphasizing esthetic and ethical ways of knowing, the patterns of knowing that students in my neonatal nurse practitioner class had the most trouble articulating in their clinical journals.

Carper (1978) emphasized esthetics as an important epistemological foundation of nursing. Esthetic patterns of knowing make possible a wider consideration of conditions, situations, and experiences. An esthetic experience involves the creation and/or appreciation of a singular, particular, subjective expression of imagined possibilities or equivalent realities which resists projection into the discursive form of language.

According to Carper (1978), esthetic knowledge has a holistic perceptual quality that can result in empathetic relation with another toward an expressive and transformative outcome. Empathy is an important mode in the esthetic pattern of knowing. One gains knowledge of another person's singular, particular, felt experience through empathetic acquaintance. The more skilled the nurse becomes in perceiving and empathizing with the lives of others, the more knowledge or understanding will be gained from alternative modes of perceiving reality.

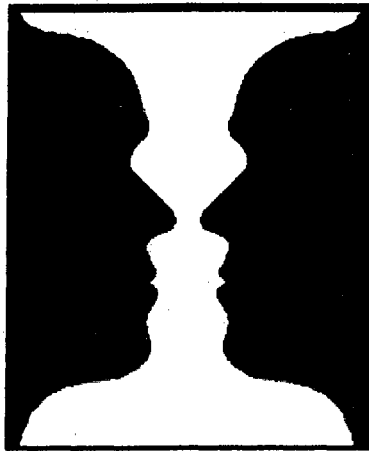
Chinn (1994) noted that "art arises from the immediate embodied grasp of the situation, the tools or instruments with which the artist works, and the intuitive knowing of what is to be created in the act" (p. 24). Chinn (1994) also recognized that the "art/act arises from non-discursive, aesthetic knowing that is unique to the moment. Like other art forms, some aspects of the original art/act can be represented symbolically through stories, photographs, drawing, or poetry" (p.

25). According to Chinn (1994) esthetic knowing involves an “embodied grasp of situations and intimate experience with the deepest and most significant life events ...like birth, death, sorrow, joy, pain and life transitions” (p. 37).

Therefore, in the current study, participants were offered the opportunity to share stories of experience in interviews as well as share artifacts collected along the way such as poetry, art, memorabilia, journals, memory books, et cetera from their experience. It is anticipated that for many mothers who have difficulty expressing their stories in narrative interviews, alternative esthetic ways of perceiving may be helpful allowing nurses greater insight into the experiences of others.

Carper extended the esthetic pattern of knowing to the ability to recognize figure and ground relationships (see Figure 1). Kvale (1996) also described the figure and ground relationship as the interaction between interviewer and participant. The figure portion of the relationship is represented in the profile of the two individuals facing one another (figure). The background (vase) represents the knowledge contained or constructed inter the views of the interviewer and the participant. This personal interrelation and the knowledge that it leads to will be important to this study in that there will be an alternating movement between focusing on the personal interaction and on the knowledge constructed through the interaction. Kvale (1996) also described this figure/ground phenomenon as the human interaction of the inter view as producing scientific knowledge.





*Figure 1.* Figure/Ground. The figure portion of the relationship is represented in the profile of the two individuals facing one another (figure). The background (vase) represents the knowledge contained or constructed inter the views of the interviewer and the participant.

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Ethics (the moral component of knowing in nursing), as described by Carper (1978) helps nurses to better understand the difficult personal choices that NICU mothers often face. These choices raise fundamental questions about morally right and wrong action in connection with the care and treatment of illness and the promotion of health. Moral dilemmas arise in situations of ambiguity and uncertainty. For nurses, knowledge of morality goes beyond the knowing of the norms and ethical codes of the discipline. It also entails understanding the values, goals and wishes of the patients in their care. Offering NICU mothers the opportunity to tell their stories provides an avenue to better understanding the individual moral concerns. These matters will be referred to as "ethics of everyday life". I believe that a fuller, more nuanced understanding of the mothers' experiences in the NICU will have implications not only for clinical practice, but also nursing education and research.

Kelly (2000) used a term coined by Schon (1983,1987) to describe the ethical nature of nursing as “swampy low ground” issues that are grounded in the contextual realities of daily life. According to Kelly (2000), when seeking greater understanding of multiple realities in solving moral problems there is an inextricable link between nursing ethics and caring. Rich (2005) suggested that “it would be a serious ethical lapse for nurses if they are not mindful of the moral nature of their day-to-day practices and if they lose, or worse, if they never develop a sense of concentrated awareness and wonder as they go about their work” (p. 18). She goes on to say, when lack of mindfulness occurs, routinization of nurses’ work becomes commonplace and matters of importance are lost to technical applications (pp.18-19). New paradigm research is critical because the researcher seeks to understand the meaning of situations by descending to the “swamp” of important problems where the rigor of positivism does not apply (Meerabeau, 1992, p.111).

Watson’s (1985) philosophy and caring theory primarily guided the present study. In recent years, the nature of nursing has been increasingly characterized as art, framed in terms of esthetic relationships and caring. Watson (1985) suggested that, although nursing is aligned with the human sciences, the beauty and strength in nursing is found in the art of human care and that knowledge of human phenomena should be informed by esthetics and intuition. It follows then, that esthetic methods that include narratives, photographs and journals are considered appropriate to the study of humans and health (Chinn & Watson, 1994; Watson, 1985; Vitz, 1990).

Watson (1985) uses the term *carative* in contrast to the more common term curative to help students to differentiate nursing from medicine. Watson explains curative factors as those that aim at curing the patient of disease, and carative factors as those that aim at the caring process that helps the person attain (or maintain) health or die a peaceful death. For Watson, the focus of nursing is concerned with the knowledge and understanding of "care" which is different from, but complementary to, the knowledge and understanding of "cure" which is in the domain of medicine.

Watson's theory creates a balanced perspective in nursing education and practice by providing a framework for addressing the mind-body-spirit of the nurse and client simultaneously during interactions (Sitzman, 2002, p. 1). Wholistic care is widely recognized as the cornerstone of nursing practice. Watson's (1985) theory of human care embraces wholeness for patients, interconnection and mindfulness or the art of awareness for nurses (Sitzman, 2002; Rich, 2005). Sitzman (2002) helped nurses in the latter by creating a bridge between Watson's theory of human caring and Thich Nhat Hanh's Zen Buddhist tradition of mindfulness.

Watson's theory of human caring suggests that nurses cultivate a daily practice of mindfulness or concentrated awareness in all of one's daily activities. Thich Nhat Hanh (1995) described mindfulness as important to help shed light on all things. To live mindfully, people have to return to life and be aware of each thing that they do (Rich, 2005). Mindfulness supports concentration. Mindfulness supports deep insight and awakening. In relation to the present study, one aspect of mindfulness is to be aware in the NICU; for instance, a poem hanging on a

child's crib, a piece of art left at the bedside by a sibling, a family photograph or scrapbook left behind by a mother to help healthcare providers see the infant as a human being with important family connections. Without mindfulness significance of these items can go unnoticed by nurses in the NICU who are preoccupied by the procedural and technological needs of the patient or who find themselves engaged in the bureaucratic duties, interests and values of the healthcare institution.

Sandelowski (2004) suggested that "qualitative research can make evidence-based practice a truly mindful as opposed to mindless or rote methodology for improving healthcare" (p. 1382). Sandelowski also noted that "qualitative health researchers should take more stock in our stories: to showcase what and how they reveal, clarify, distill, elaborate, extend, complicate, confirm, refute, explain, reframe, personify, individualize, specify, sensitize, persuade, evoke, and provoke" (p. 1382). It is important for researchers in practice disciplines, according to Sandelowski, to conduct transformative inquiry, to show the beneficial outcomes of these revelations, clarifications, distillations, elaborations, extensions, and the like. Not only should qualitative researchers in nursing emphasize the artfulness in our studies, we should also incorporate our qualitative research findings as evidence in evidence-based practice.

Rich (2005) proposed that Zen Buddhism based on the tradition of Thich Nhat Hanh has value for nursing ethics. According to Rich, further insights can be gained from Zen tradition which acknowledges the interconnection among all people rather than reinforcing separatism and dualism. She advocated practicing mindfulness daily and building a strong nursing community.

Watson (2005) has said, "it is when we include caring and love in our science, we discover our caring-healing professions and disciplines are much more than a detached scientific endeavor, but a life-giving and life-receiving endeavor for humanity" (p. 3) My study was guided by these ideas and I will embrace these ideas as I enter into relationships with the study participants.

Influenced by Carper's ideas and by Watson's theory of nursing, I then turned to researchers Munhall (2007) and Sandelowski (1991, 1994, 2004) to establish a better understanding of the research possibilities that would be fitting for my beliefs and values. I soon became interested in narrative inquiry because stories seemed to be a natural part of my clinical experience with mothers.

I also studied the works of other researchers who had focused much attention on narrative inquiry, beginning with Charon (2006) who proposed that narrative means might help bridge the divides between healthcare practitioners and patients through common understandings and shared ways of knowing about illness and that this connection offers opportunities to improve the effectiveness of care. Charon (2006) recommended that narrative researchers examine five features of narrative including: a) temporality; b) singularity; c) causality/contingency; d) intersubjectivity; e) ethicality. I will elaborate on these five features of narrative in Chapter V Constructing and Managing Narrative Text.

Frank (1995) noted that "Thinking with stories is the basis of narrative ethics" (p. 158). Frank (1995), provides lessons for individuals to follow when thinking with stories, these include: (a) Do not move on once the story has been heard, but continue to live in the story, becoming in it, reflecting on who one is becoming, and gradually modifying the story; (b) attend to how a story is *used* on

different occasions of its telling; there is always another story. This lesson means that life is lived in decisions, each setting in place a different way of telling the story. Many decisions because they have consequences are moral; (c) some of the most unfortunate medical decisions are made when there is a breakdown in the continuity of relationships and of story; (d) thinking with stories does not offer people clear guidelines or principles for making decisions, instead, what is offered is permission to allow the story to lead in certain directions, invoking narrative knowledge to help make professional decisions; (e) narrative ethics takes place in telling and listening (pp. 158-163). Frank (1995) proposed that there is a need for ill people and their families to tell their stories in order to construct new maps and new perceptions of their relationship to the world.

Frank (1995) indicated that heuristic frameworks can help us hear stories by disentangling types of narratives; they can help in recognizing what basic life concerns are being addressed and how the story proclaims a certain relation of the body to the world. "Heuristics is a form of phenomenological inquiry that brings to the fore the personal experience and insights of the researcher" (Patton, 2002, p. 107). According to Patton (2002), the root meaning of heuristic comes from the Greek word *heuriskein*, meaning to discover and find. The foundational question of heuristic inquiry is: What is my experience of this phenomenon and the essential experience of others who also experience this phenomenon intensely? (p. 107)

The primary developer of heuristic inquiry, Moustakas (1994) offered the following approach: First, immersion in the setting starts the inductive process. Second, the incubation process allows for thinking, becoming aware of nuance

and meaning in the setting, and capturing intuitive insights to achieve understanding. Third, there is a phase of illumination that allows for expanding awareness. Fourth, and most understandably, is a phase of explication that includes description and explanation to capture the experience of individuals in the study. Finally, creative synthesis enables the researcher to synthesize and bring together as a whole the individuals story, including the meaning of the lived experience.

The framework that Frank (1995) suggested provides a means of heightening attention to stories that are in themselves their own truth. "Listening is hard, but it is also a fundamental moral act; to realize the best potential in postmodern times requires an ethics of listening" (Frank, 1995, p 25).

Narrative research appears to fit within the caring-healing and holistic framework of nursing. Narrative inquiry allows for the restoration of core values of caring relationships including empathy, compassion, and love. Narrative research fosters a more intimate alliance between nurse and patient in clinical practice, and between nurse researcher and participant in nursing inquiry.

Holloway and Freshwater (2007) suggested that narrative research attempts to rehabilitate the person, restoring the experiencing person to the center of inquiry, and is akin to a humanistic and holistic approach to patient care; that is to say that narrative research is person centered as opposed to self-centered. Narrative inquiry also locates not only the participants but also the researcher firmly in the process. A narrative approach to nursing inquiry is consistent with the values and goals suggested by nursing frameworks and

theories guiding my study (for example, Jean Watson, Barbara Carper, Margarete Sandelowski).

Narrative research in nursing has a relatively new history. Frid, Ohlen, and Bergbom (2000) argued that narratives are presented both as a method of nursing research and as a way of presenting (improved) knowledge about nursing care. In their discussion they report that the term 'narrative' first appeared in the nursing literature in 1997, based on a search of CINAHL (Cumulative Index of Nursing and Allied Health Literature). Their findings suggest that narrative research in nursing remains a relatively young and innovative method. Many authors committed to the concept of caring in nursing were developing narrative inquiry earlier than 1997, but some may have struggled to be accepted for publication in indexed journals. For example, see Benner (1994); Benner, Tanner, and Chesla (1996); Sandelowski, (1991); Vezeau (1993a, 1993b, 1994).

Some qualitative researchers in nursing that have focused on stories and narrative as an object of inquiry and those that have been particularly influential in this study include Ayres (2000a, 2000b); Benner (1994); Benner, Tanner & Chesla (1996); Duffy (2007); Poirier & Ayres (1997); Sandelowski, (1991, 1994); Sandelowski and Jones, (1996) and Vezeau (1994). These authors have suggested narrative approaches that can be developed by nurses and these will be discussed in greater detail in chapter three, which focused attention on literature review of narrative inquiry.



## Summary

“Understanding the narrative context of illness provides a framework for approaching a patient’s problems holistically, as well as revealing potential diagnostic and therapeutic options which we ignore at the patient’s peril” (Greenhalgh & Hurwitz, 1998, pp. 6-7). Greenhalgh and Hurwitz (1998) suggested many reasons to study narratives: In the diagnostic encounter, narratives are the phenomenal form in which patients and families experience ill health; encourage empathy and promote understanding between clinician and patient and family; allow construction of meaning, and may supply useful analytical cues and categories. In the therapeutic process, narratives encourage a holistic approach to management, are themselves intrinsically therapeutic or palliative, and may suggest or precipitate additional therapeutic options. In the education of patients and professionals, narratives are often memorable, are grounded in experience, and enforce reflection. In research, narratives set a person-centered agenda, challenge received wisdom and generate new hypotheses (Greenhalgh & Hurwitz, 1998, p. 7).

While narratives have much to offer, it is equally as important to acknowledge the silences. When mothers are face-to-face with the uncertainty and ambiguity of the NICU, their lives are often turned inside out. They are suddenly facing the threat of loss or the impending death of a child. They oftentimes, find it too difficult to talk openly about their experiences, especially when life circumstances are the most trying. Poirier and Ayres (1997) noted that storytellers may on occasion use “a panicked flight of language, veering away from one subject into another, equally unpleasant thought, careening across

memories that seem to offer few pleasant harbors” (pp. 555-556). Poirier and Ayres (1997) explained that where there are inconsistencies, repetitions, and omissions in the telling, this may be an indication of a traumatic experience. Wilkan (2000) noted that the narrative researcher needs to be able to recognize, acknowledge and honor the silences and the “continuous groping for meaning” that determines the narrative structure of lived experience (p. 268). This needs to be done with sincerity, fragility, and with appreciation for the circumstances.

The following study was conceptualized during what I perceived to be an ordinary day in the NICU and then suddenly found it to be an extraordinary day as I entered into relationships with mothers and found in these relationships meaningful accounts of their experience. Accounts expressed not only in the stories the mothers told but also in poetry, shared photographs, memory books, diaries, et cetera which provided access to their moral concerns and values, concerns and values that may not have otherwise been revealed.

Later I began to think about my own experience as a nurse practitioner in relationship with these mothers and at that moment I became acutely aware of the nuances and meanings found in stories, journals, poetry, art, photographs, etc. that too often go unnoticed by nurses in clinical practice including myself. I began to examine qualitative research approaches and in particular aesthetic methods (Chinn & Watson, 1994; Munhall, 2007; Sandelowski, 1991; Sandelowski & Jones, 1996; Watson, 1985). Finally, the focus of the study narrowed to include personal narratives told to me in qualitative interviews with mothers who have experienced the NICU and also incorporated stories told to me about personal artifacts collected by mothers while spending time in the

NICU. Specifically, focusing on the dominant moral and existential concerns expressed in mothers' stories.

Watson (1985) recognized that if we want to produce therapeutic results in the persons being served, we need to begin by listening to their stories. Suffering calls for a moral response, a "committed active, respectful and confirming listening" (Charon, 2006, p. 180). "The meanings of stories are themselves part of the moral fabric of experience" (Hester, 2001, p. 64). If we as care providers want to facilitate understanding and improvements in care it is necessary to begin by listening.

My research seeks to understand the world of human concerns, meanings, silences and taken-for-granted aspects of everyday life, presented by the participants in personal stories and through the artifacts collected during the participants' experiences. It is hoped that the reader is challenged to consider the power of understanding stories in everyday clinical practice and that the meanings embedded in stories and artifacts are recognized and made visible. It is important to consider how the stories told by mothers in the NICU will help shape practices of educators and healthcare providers in ways respectful of the stories they disclose.

For this to happen, practitioners must be present with ourselves in the moment to moment interactions with our patients and we must also be mindful of the ease with which we turn away, focusing on the more technical and procedural aspects of care, forgetting that attentiveness, carefully listening and hearing the voices and concerns inherent in stories and artifacts are also important aspects of a caring and committed relationship with others.

Narrative inquiry offers an alternative to quantitative studies geared toward randomized controlled trials, which do not capture knowledge based in particularity, contextuality, temporality, relationality, ethicality, and aesthetic experience. Because this study is concerned with the life world, human concerns, experiential notions of the good, narrative inquiry is a preferred methodological choice. Holloway and Freshwater (2007), suggests that narrative inquiry examines the process and product of nursing, suffering and caring in a meaningful way (p. 30).

Helping nurses to better understand the stories patients share with them can provide new insights for clinical practice including the meaning of the experience for the patient and/or family, ways of coping with suffering and loss, and ways in which nursing and medical care can be more responsive to the existential and moral concerns of our patients and their families.

## CHAPTER II

### THE NATURE OF THE STUDY

#### Introduction

In chapter one, I situated myself within narrative inquiry. As I proceed with chapter two, I clarified the purpose and aims of the study, identified research questions and presented justification for studying mothers' stories.

#### Purpose and Aims

The purpose of this qualitative study was to seek descriptions (stories) of mothers NICU experiences. There were three specific aims: (a) To describe stories of mothers' NICU experiences, (b) to describe meaning in stories, and (c) to illuminate the ethical concerns embedded in mothers' stories.

#### Research Questions

Research based on studying whole persons in context and in time through narratives of their experience requires a major shift in perspective and approach. In order to examine notions of the good life, what is worth being and preserving for mothers, one must study everyday ethical concerns and narratives of the mothers who have experienced having an infant in the NICU. The stories told by mothers can provide the necessary background for promoting understanding for everyday ethical (moral) concerns and can help the practitioner to seek ways of enriching and transforming that experience for mothers.

Rather than form hypotheses, the narrative researcher frames questions for exploration. The research questions addressed in this study were:

1. What stories are told by mothers who have had the experience of having a baby in the neonatal intensive care unit (NICU)?
2. What do the stories reveal about the mothers' search for meaning?

3. What ethical concerns are represented and constructed in the stories told by mothers?
4. How might mothers' stories be viewed to improve care providers understanding of what is most common, most taken-for-granted and what concern mothers' most so that quality care can then be provided?

The research questions were held tentatively and allowed to be challenged, altered, extended, and transformed by what was learned in the field. The ability to have initial questions challenged is an essential discipline of interpretive inquiry (Benner, 1994).

#### Relevance of the Study

The reason to focus on narrative inquiry is to better appreciate the value of each mothers' unique way of attaching meaning to their experience.

Widdershoven and Smits (1996) argued that the point of narrative research is to make explicit the view of the good life, embodied in stories. This involves a process of interpretation in which the perspective of the researcher and that of the story are merged into a new view of how to live (Widdershoven & Smits, 1996, p. 276).

Many leaders in narrative inquiry (Benner, 1991; Charon, 2006; Frank, 1995; Nussbaum, 1986) have concluded that stories are essential ingredients of ethical healthcare practices. Stories not only tell us about the experiences of others, but they give insight into the nature of practices as ethical endeavors. I hope that this study will illustrate how mothers' stories have the potential to open dialogue about issues of perceived meaning and morally salient concerns. A mother's story may express a new view of the good life thereby enriching our clinical practice and contributing to our understanding of the mothers' needs, hopes,

values and desires. A mother's story about a potential or possible problematic issue in the NICU can also give healthcare providers a new perspective on how to deal with issues of health and illness for clinical practice. For this to occur, however, stories have to be integrated into our practices. I believe that this study will show the potential mothers' stories have to inform healthcare care practices so that all mothers can receive optimal, timely, informed and ethical care.

### Summary

This study was guided by my clinical practice. I wanted to better understand the stories mothers tell about their NICU experiences, particularly the ethical concerns embedded in their stories. As I encountered their stories in everyday clinical practice, I began to form the research questions that were presented. Based on the purpose of the study, I chose to seek answers to the research questions through a methodological approach known as narrative inquiry.

Narrative inquiry is an appropriate methodological choice because it allows for the systematic study of personal experiences and meanings. Narrative inquiry is also a method that remains sufficiently open and flexible to permit exploration of mothers' experiences.

There is no single method of narrative analysis, but a spectrum of approaches to texts that take a narrative form. Methods of narrative analyses center on stories as the object of investigation. They aim to identify themes and/or narrative structures.

Storytelling is a relational activity that encourages others to listen, to share, and to empathize. It is a collaborative practice and assumes that tellers

and listeners interact in particular cultural milieus and historical contexts, which are essential to interpretation. In this study, attention to mothers' narratives is particularly important because they open discursive spaces for mothers to recollect their experiences of the NICU with all its ethical complexities. Health professionals have much to learn from them.



## CHAPTER III

### REVIEW OF PERTINENT LITERATURE ON NARRATIVE

**"All sorrows can be borne if we can put them into a story"**  
(Isak Dinesen, as quoted in H. Arendt (1958), *The Human Condition*, p. 175)

#### Historical Background

The turn to narrative has been influenced by various disciplines including history, literature, psychology and anthropology. In locating narrative historically, Pinnegar and Daynes (2007) explicated four narrative turns: the attention to relationships among participants, the move from numbers to words as data, the focus on the particular, and the recognition of blurred genres of knowing.

In turning to narrative inquiry, relationships between researcher and researched was reconceptualized from an objective and distanced position to a relational and interactional view. Narrative researchers value participants as individuals with histories that exist in time and as embedded in context.

In the move to turn from numbers to words as data, narrative researchers seek to understand participants' explanations (words) of particular events, nuanced meanings, and values rather than to transcribe experiences to numeric codes to be labeled, counted and generalized to a larger population.

Narrative researchers move from a focus aimed at generalizability to a focus that seeks to understand the particular experience, in a particular setting, involving particular people. These accounts offer a potentially deeper and more complex understanding of individual experiences.

The turn to narrative is accepting of multiple ways of knowing the world and is interested in establishing findings through authenticity, resonance, or trustworthiness rather than an exclusive reliance on positivistic forms of knowing.

## Contemporary Narrative Inquiry

Contemporary narrative inquiry offers a diverse collection of analytic lenses, approaches and voices from which to view qualitative material, which tends to be shaped by the interests and assumptions embedded in the researchers' discipline (Chase, 2005). Chase (2005) outlines five analytic lenses through which contemporary researchers can approach empirical material: narrative as a form of discourse, narrative as verbal action, narrative as both enabled and constrained by a range of social resources and circumstances, narratives as socially situated interactive performances, researcher as narrator as they develop interpretations and find ways in which to present or publish their ideas about the narratives they studied (pp. 658-660).

The first approach, outlined by Chase (2005), focuses on the relationship between individuals' life stories and the quality of their lives, particularly their psychological development. The second approach highlighted by Chase (2005) is the "identity work" that people engage in as they construct selves within specific institutional, organizational, discursive, and local cultural contexts. Another approach that many researchers share is an interest in the *hows* and *whats* of storytelling but base their inquiry on intensive interviews about specific aspects of people's lives rather than on conversations in specific organizational contexts. Anthropologists have approached narrative inquiry using a fourth approach called *narrative ethnography*, which is a transformation of both the ethnographic and life history methods. These methods tend to present the researcher and the researched together within a single multivocal text focused on the character and process of the human encounter. Narrative researchers have

also turned their analytic lens on themselves in *autoethnography*, here researchers write, interpret, and/or perform their own narratives about culturally significant experiences. (Chase, 2005, pp. 658-660).

### Illness Experience and Narrative

There has been a growing trend toward narrative research over the past decade, especially in research on illness narratives of a variety of diverse conditions. The following illustrates the use of narrative research: AIDS (Marshall & O'Keefe, 1995), bowel disease (Kelly & Dickinson, 1997), cancer (Bell, 1999; Del Vecchio Good, Munakata, Kobayashi, Mattingly, & Good, 1994; Frank, 1995; Mathews, Lannin, & Mitchell, 1994; Woodgate, 2006), detection of fetal anomalies (Sandelowski & Jones, 1996), physical disability (Borkan, Quirk, & Sullivan, 1991; Mattingly, 1998; Phillips, 1990), infertility (Becker, 1997; Riessman, 2000), epilepsy (Good & del Vecchio Good, 1994), mental illness (Capps & Ochs, 1995; Hyden, 1995; Saris, 1995), multiple sclerosis (Robinson, 1990), musculo-skeletal disorders (Garro, 1994) and rheumatoid arthritis (Bury, 1982; Williams, 1984).

Although some research on the NICU experience from a mother's perspective exists, this research has focused on associated stressors (Singer, Salvator, Guo, Collin, Lilien, & Baley, 1999); effects on the family (Doucette & Pinelli, 2004), post-traumatic stress due to childbirth (Beck, 2004; Callahan & Hynan, 2002; DeMier, Hynan, Harris & Manniello, 1996; Holditch-Davis, Bartlett, Blickman & Miles, 2003), anxiety & depression (Beck, 2003; Davis, Edwards, Mohay & Wollin, 2003; Gennaro, 1988; Horowitz, Damato, Duffy & Solon, 2005 ), worry (Docherty, Miles & Holditch-Davis, 2002) coping mechanisms (Melnyk,

Albert-Gillis, Feinstein, Crean, Johnson, Fairbanks, Small, Rubenstein, Slota, Corbo-Richert, 2004), perinatal loss (Cote-Arsenault & Marshall, 2000); and grieving (Dyer, 2005a, 2005b; Golish, T. D. & Powell, 2003) etc. Whereas, scant attention has been paid to the traumatic aspect of the NICU experience on mothers' and their search for meaning through storytelling and aesthetic modes of expression.

### Narrative Inquiry in Nursing

Narrative inquiry is not new to nursing. Vezeau (1993a) examined original works of fiction in a scholarly investigation of narrative as aesthetic method. She found that narrative inquiry can expand nursing's knowledge of particular situations which will expand the experience of commonalities of women and families in health and transition.

Sandelowski (1991) explored narrative approaches in qualitative research and noted that narrative approaches to qualitative research affords nursing scholars a special access to the human experience of time, order, and change, and it obligates us to listen to the human impulse to tell tales. Sandelowski (1994) also brought attention to narrative knowing in nursing practice. She studied the nature and function of stories for patients, the location of stories in the diagnostic and healing functions of the nurse, and the significance of stories for a particular vision of holistic nursing practice and concluded that narratives are an expression of human consciousness and a means to expand it and thus move toward the wholeness that defines health. She noted that stories are the primary text for practice and research. Holistic nursing practice mandates

developing expertise in the skills of narrative analysis and (re) construction, skills that help the nurse to recapture what is essentially human in health care.

Sandelowski and Jones (1996) described how a small group of couples who learned during pregnancy that their baby was impaired managed their encounter with choice by how they “storied” it. They proposed that couples’ narrative constructions of choice in the aftermath of a positive fetal diagnosis (meaning the fetus was found to be impaired) were efforts to create “healing fictions” to come to terms with a devastating experience. Fictions, as described by the researchers are not false, but rather strategic arrangements of emplotments or emplotments of “objective” events and “phenomenological” reality intended to impose order, confer meaning, and provide psychic comfort (p. 354).

Ayres, Kavanaugh and Knafel (2000), described individual accounts of family care giving using a combination of across-case thematic analysis and within-case, narrative analysis to develop a typology of stories for family caregivers in order to explore the variety of meanings caregivers brought to and made from their experiences. Ayres (2000a) identified four narrative types in the tradition of Frank (1995) and Hawkins (1993). Ayres (2000b) noted that both researchers and clinicians can benefit from interpretive methods that offer access into the process and products of making meaning through stories.

Poirier & Ayres (1997) suggested that as qualitative researchers use narrative inquiry to find meaning in the stories told by research participants, they also need to develop sensitivity to unspoken or indirect statements, which is central to interpretation. They offered tools of “overreading” in order for narrative

researchers to attend to inconsistencies, endings, repetitions, and silences. They also offered guidance for narrative researchers on how far to probe, noting that there are times an interviewer may need to leave a silence unexplored in order to protect emotions or memories that are too painful for the participant to recall.

The research on illness narrative(s) have primarily been viewed from first-person accounts of illness in terms of autobiography or biography. However, when the patient is an ill or prematurely born infant requiring care in the NICU, the most-likely person to tell the story of the infants' struggle for life or a meaningful death often rests with the mother. Perhaps, one of the best ways to begin to understand this experience as a clinician and researcher is to bear witness to the mother's story.

This study aims to investigate stories mothers tell about their experience of having an ill or premature infant in the NICU, a subject that has not previously been studied from a narrative perspective. As such, this study seeks to contribute to the growing literature on illness narratives and narrative analysis. However, it also has a second purpose. Unlike most studies using narrative analysis, this study will extend an ethic dimension to the narratives of maternal experience. In particular, this study will seek to examine how women with a premature or ill infant story the "ethics of everyday life" and how mothers attempt to construct coherence out of the distress and disorder caused by their infant's illness. The proposed study also seeks to clarify how narrative analysis has much to contribute to nursing education with particular attention to esthetic values and an orientation to the ethical:

## Clarification of Terms

Before proceeding to the theoretical and conceptual influences, it is important to clarify the terms that narrative researchers use to describe the empirical material they study. First, narrative researchers must acknowledge that terms in narrative inquiry have flexible meanings, beginning with narrative itself. The use of the term "narrative" in everyday conversation is obscure.

Some scholars have used the term "narrative" and "story" synonymously (Frank, 1995; Lieblich, Tuval-Mashiach & Zilber, 1998; Polkinghorne, 1988; Riessman, 1993). Other narrative researchers distinguish between stories and narratives (Connelly & Clandinin, 1990). Connelly & Clandinin (1990) define stories of experience by saying that it is equally correct to say "inquiry into narrative" as it is "narrative inquiry" (p. 2). By this they mean that narrative is both a phenomenon and a method. Narrative names the structured quality of experience to be studied, as well as the patterns of inquiry for its study. To preserve this distinction, many narrative researchers use the reasonably well-established device of calling the phenomenon "story" and the inquiry "narrative" (p. 2). Thus, Connelly and Clandinin (1990) contend that people by nature lead storied lives and tell stories of those lives, whereas narrative researchers describe such lives, collect and re-tell stories of them, and write narratives of experience.

Wilkan (1995) has written against "narrative", arguing that "story" serves us quite as well if not better (p. 264). According to Wilkan (2000), "story" is experience-near, probably in every language, whereas "narrative" may be so only

among middle class, educated Americans, and European researchers and academics (p. 217).

Most children are able to identify a story even if they are not able to provide a definition that would satisfy an academic. McAdams (1993) described the basic structure of story as follows: First we know that a story has a setting that locates the reader in a time and place. Second, a story will have human or humanlike characters that experience an initiating event that motivates the character to make the attempt to attain a certain goal. The character intends to reach the goal smoothly, but inevitably the plot thickens when the character encounters barriers blocking their smooth transition toward their desired goal. The barrier to goal achievement has consequences for the character leading to a reaction. The reader of the story is interested in how the story will extend forward to future episodes. One episode follows another each containing the same structural sequence. Episodes build and story takes form (McAdams, 1993, pp. 24-27).

For the purposes of this study, I used narrative and story synonymously. I defined narrative using Riessman's (1993, 2008) definition:

The term narrative includes essential ingredients. In everyday oral storytelling, a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story. Events perceived by the speaker as important are selected, organized, connected, and evaluated as meaningful for a particular audience. (p. 3)



There are several types of stories that narrative researchers refer to in narrative inquiry. *Life story* is a story that arises from lived experience. It is a retelling of one's life as a whole in the voice of the teller, as it is remembered and in a language that is deeply felt. Life stories serve as an excellent means for understanding how people see their own experiences, their own lives, and their interactions with others. They allow researchers to learn more than almost any other methodology about human lives and society from one person's perspective (Atkinson, 2007, p. 241).

*Personal Experience Narratives* "encompass long sections of talk or extended accounts of lives in context that develop over the course of single or multiple research interviews or therapeutic conversations" (Riessman, 2008, p. 6). *Personal narrative* refers to talk organized around consequential events. A teller in a conversation takes a listener into a past time or "world" and recapitulates what happened then to make a point, often a moral one (Riessman, 1993, p. 3). Personal experience narratives often draw upon the public, oral storytelling tradition of a group and draw their meaning from the common understandings that exist within the group, although they do express the "private" folklore or meanings of the teller. They are often based on anecdotal, everyday experience, commonplace experiences. They have a structure, i.e., a beginning, middle and an end. They do not necessarily position the self of the teller in the center of the story, as self stories do (Denzin, 1989, p. 44), although they may. Their focus according to Denzin is on shareable experience. They create an emotional bond between listener and teller. They express a part of the "inner life" of the storyteller (Denzin, 1989, p. 44).

Mattingly (2007), suggests that narrative is something that can be acted as well as told. "*Acted or performed narratives*", according to Mattingly (2007) are "*healing dramas*" that occur in clinical practice and in life. They are the emergent, improvised, and socially orchestrated employment of action. Healing dramas reveal life in breach and suggest healing possibilities. An awareness of healing dramas can help nurses to better understand how our work fits into the life world of our patients and their families (Mattingly, 2007, pp. 405-425).

Dramatic time, according to Mattingly (2007) is a time when we would say something significant is happening (Mattingly, 2007, pp. 405-425). In dramatic moments, time itself takes on narrative shape and is imbued with those qualities that are the essential ingredients of a good story: suspense, riskiness, trouble, enemies, desire, transformation, and plot (Mattingly, 1994, 1998). Mattingly (2007) explained, that dramatic time is not about progress. It is characterized by the suspense of not knowing whether a desired ending will come about, and the suspense of wondering whether the ending one pictures is the one that will still be desired or possible as the story unfolds.

*Fiction* is something made up or fashioned out of real and imagined events and experiences. Riessman (1993) clarified the narrative truth versus historical truth debate by saying that narratives reveal a truth—not an objective truth, but the truth of experience. In this sense, it follows that the way in which a given event narrative is organized reflects the experience of the narrator, the way in which he/she has or has not been able to subjectively work through the event, give it meaning and integrate it into his/her biography (Riessman, 1993, p. 64). Fictions, as described by Sandelowski and Jones (1996), are not false, but rather

strategic arrangements of emplotments or emplotments of “objective” events and “phenomenological” reality intended to impose order, confer meaning, and provide psychic comfort (p. 354).

*Interpretive biography* is defined as the studied use and collection of life documents, or documents of life (Plummer, 1983, p. 13), which describe turning-point moments in individual lives. These documents will include autobiographies, biographies, diaries, letters, obituaries, life histories, life stories, personal experience stories, oral histories, and personal histories (Denzin, 1989, p. 7). Denzin (1989) defined interpretive biography as creating literary, narrative accounts and representations of lived experiences.

*Experience* refers to individuals meeting, confronting, passing through, and making sense of events in their lives and experiences and are given expression in a variety of ways, including rituals, routines, myths, novels, films, scientific articles, dramas, songs sung, and lives written about in autobiographies and biographies (Denzin, 1989, p. 33).

*Esthetic (a.k.a. Aesthetic) expression* attempts to capture the life-world and meanings of human beings. Esthetic expression can take many forms such as storytelling, art, photographs, paintings, drawings, poetry, memorabilia, music, dance, journaling, etc. Esthetic expression has been used as a device for triggering shared reflection in narrative inquiry (arts-based narrative inquiry) and has been used as a tool for narrative analysis, informing the meaning made from field text to research text (arts-informed narrative inquiry). The esthetic force of narrative has been linked to its healing powers (Mello, 2007, pp. 203-223). Attempting to better understand patient’s use of art and narrative is one way to

help nurses find meaning in their clinical encounters (Eifried, Riley-Giomariso, & Voigt, 2001). This study seeks to honor multiple esthetic perspectives.

*Empathetic stance* is a way of approaching data that allows for discovery rather than seeks confirmation of hypotheses and that fosters more exhaustive quests for explanation rather than the illusion of finding a preexisting truth. An empathetic stance orients researchers to other people's experience and meaning-making, which is communicated to us through narrative (Josselson, 1995, p. 32).

According to Josselson (1995), research that approaches data with an empathetic stance provides opportunities to overcome distance rather than creating it. The indeterminacy between the subject and object thus becomes a resource rather than a threat. As both a tool and a goal of narrative inquiry, empathy is premised on continuity, recognizing that kinship between self and other offers an opportunity for a deeper and more articulated understanding. Empathy becomes an attitude of attention to the real world based in an effort to connect ourselves to it rather than to distance ourselves from it. Josselson (1995) notes that an empathetic stance takes hermeneutics (see definition below) as its epistemological ground, for when we study whole human beings, we are aiming to interpret others who are themselves engaged in the process of interpreting themselves (Josselson, 1995, p 30-31).

*Bearing witness* is "committed active, respectful, confirming listening" (Charon, 2006, p 180). *Bearing witness* requires a "generosity of self in the service of another self, trying to be heard" (Charon, 2006, p. 184). Charon (2006) noted that "bearing witness to suffering helps us to overcome some of illness's

pernicious divides—relation to mortality, contexts of illness, beliefs about causality, and the emotions of shame, blame, and fear and how they culminate in isolating patients from those who care for them” (p. 198).

*Interpretative practice* consists of the activities through which persons understand, make sense of, organize, and represent experience, which creates the conditions for understanding. The interpretive process depends on the aims of the research. This study aims to explicate context of meaning and world rather than to uncover universals or laws. Therefore the mode of interpretation used in this study is hermeneutic, where the process of inquiry flows from the question—which is a question about a person's inner, subjective reality and, in particular, how a person makes meaning of some aspect of his or her experiences through storytelling and supplemental forms of expression.

*Understanding* that there are multiple ways of knowing and understanding human experience has been described as a “blurred genre”. Denzin (1989) noted that the dividing line between fact and fiction also becomes blurred in narrative text, for if an author can make up facts about his or her life, who is to know what is true and what is false? The point is, as Denzin noted, that if an author thinks something existed and believes in its existence, its effects are real. Since all writing is fictional, made-up out of things that could have happened or did happen, it is necessary to do away with the distinction between fact and fiction (p. 25). Denzin contends that the meanings of these experiences are best given by the persons who experience them. The preoccupation with validity, reliability and generalizability is set aside in favor of a concern for meaning and interpretation (p. 25).

Understanding involves being able to grasp the meanings of an interpreted experience for another individual. Understanding is an intersubjective, emotional process. Its goal is to build shareable understandings of the life experiences of another. This is also called verisimilitude or “truth-like,” intersubjectively shareable emotional feelings and cognitive understandings (Denzin, 1989, p. 28).

*The hermeneutical perspective*, with its emphasis on interpretation and context, informs narrative studies. A *hermeneutic approach* is used to interpret and understand narratives and the human experience the narrative is about. The narrative is a hermeneutic project in itself because it is by narration that we structure our interpretations of the world (i.e. narration is the core of understanding, which was the first interest of hermeneutics). By analyzing the way the narratives of the world of the respondent are structured, interpreting texts can then be accomplished. The interpretation of meaning is characterized by a *hermeneutic circle or spiral*. The understanding of a text takes place through a process where the meaning of the separate parts is determined by the global meaning of the text (Patton, 2002, pp. 113-115). Van Manen (1990) explained that “to do hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the life world, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal” (p. 18).

*Narrative research or narrative inquiry* is a methodology of qualitative research. *Qualitative research* is research that is inherently inductive and rooted in phenomenological or hermeneutic forms of inquiry (Josselson, Lieblich, &

McAdams, 2003; Morse & Mitcham, 2002; Patton, 2002). Narrative inquiry is a way of understanding human experience through stories. The phenomenon under study then is from an emic perspective, that is, from the perspective of a non-experimenter or non-observer. Narrative inquiry is conducted in a naturalistic setting. Narrative inquiry "requires collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus" (Clandinin & Connelly, 2000, p. 20). "An inquirer enters this matrix in the midst and progresses in the same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of the experiences that make up people's lives, both individual and social." (Clandinin & Connelly, 2000, p. 20).

*Narrative Data* are the empirical material and objects for scrutiny. Different kinds of texts can be viewed narratively, including spoken, written and visual materials. Examples of narrative data include: diaries, poetry, music, archival documents, medical records, photographs, artwork, literature (Clandinin, 2007; Riessman, 2008).

*"Narrative Analysis* refers to a family of methods for interpreting texts that have in common a storied form" (Riessman, 2008, p. 11). Riessman (2008) identified four broad typologies to narrative analysis: (1) thematic narrative analysis which interrogates "what" is spoken (or written); (2) structural narrative analysis which tells "how" a story is told; (3) Dialogic/Performative narrative analysis examines how talk among speakers is interactively produced and performed; and (4) visual narrative analysis which describes images as data to be interpreted alongside words of the image-makers (p. 19).

## Narrative Frameworks

The skeletal frameworks of Sandelowski (1991) and Josselson and Leblach (2003) informed and served as the internal structure thereby enabling observations, interviews and analysis to proceed. Morse and Mitcham (2002) noted that qualitative inquiry proceeds by identifying and developing skeletal framework. A narrative approach will guide this study as described by Sandelowski (1991). Accordingly, narrative is a framework for understanding the human being as subject of nursing inquiry, conceptualizing the interview, and analyzing and interpreting the data.

According to Sandelowski (1991), narration constitutes the following: (a) causal thinking, in that stories are efforts to explore questions of human agency and explain lives; (b) historical (as opposed to scientific) understanding that events cannot be explained except in retrospect; (c) moral enterprise, in that stories are used to justify and serve as models for lives; and (d) a kind of political undertaking, in that individuals often struggle to create new narratives to protest a perceived "storylessness" in the old ones (p. 163).

Josselson and Leblach (2003) also offer a framework for writing narrative research proposals aimed at helping students wishing to write master's and doctoral theses using narrative approaches. They recommend that students using narrative approaches include statements about the (a) background of the study; (b) research question and its significance; (c) plan of inquiry; (d) approach to analysis; (e) significance of findings; and (f) a reflexive statement about the position of the researcher in relation to the work. However, they encourage creativity and flexibility (p. 262).



## Theoretical and Conceptual Influences in Narrative Inquiry

In this section, I explore a body of theoretical knowledge and conceptual influences which have inspired and enlightened this study by the depth and diversity of approaches that the authors have taken. These theoretical and conceptual influences will guide the research process by allowing conceptual fields within which to understand mothers' stories of their infant's illness.

Czarniawska (2004) suggests that narrative inquiry does not offer a set method, or a set of procedures to check the correctness of the results. However, narrative researchers have at their disposal an ample "bag of interdisciplinary tools and techniques" to help steer the inquiry and permit analysis (p. 136).

Clandinin and Rosiek (2007) offer one theoretical framework for navigating narrative inquiry that emerged from Dewey's theory of experience. Framed within a Deweyan view of experience, narrative inquiry is not only on individual experience but also on the social, cultural, and institutional narratives within which individuals' experiences are constituted, shaped, expressed, and enacted. Narrative inquirers, according to Clandinin and Rosiek (2007) study the individual's experience in the world, an experience that is storied both in the living and telling and that can be studied by listening, observing, living alongside another, and writing and interpreting texts.

Connelly and Clandinin (2006) identified "three commonplaces or touchstones of narrative inquiry—attention to temporality, sociality, and place—which specify dimensions of an inquiry space" (p. 479). The first commonplace, temporality, attends to Dewey's notion of continuity in experience—that is, that every experience both takes up something from the present moment and carries

it into the future experiences. Events, people, and objects under study are in temporal transition and narrative inquirers describe them with a past, a present, and a future (p. 479).

The second commonplace identified by the authors, sociality, points toward the simultaneous concern with both personal and social conditions. This commonplace connects with Dewey's notion of interaction—that is, that people are always in interaction with their situations in any experience. Personal conditions are “feelings, hopes, desires, aesthetic reactions, and moral dispositions” of the inquirer and/or participant (Connelly & Clandinin, 2006, p. 480). By social conditions, the authors draw attention to the existential conditions, the environment, surrounding factors and forces, people and otherwise, that form the individual's context.

Connelly and Clandinin (2006) specified another important dimension of the commonplace of sociality which is the relationship between the participant and inquirer. “Narrative inquirers are always in an inquiry relationship with participants' lives. They cannot subtract themselves from the relationship” (p. 480). Narrative inquirers throughout each inquiry are in relationship, negotiating purpose, next steps, outcomes, texts, and the other concerns that go into an inquiry relationship. Nor can they pretend to be free of contextual influences themselves. In narrative inquiry, research questions and text are ones where inquirers give an account of who they are in the inquiry and who they are in relation to participants.

Again, drawing on Connelly and Clandinin (2006), the third commonplace, *place* or sequences of places, draws attention to the centrality of place, that is, to

“the specific concrete, physical, and topological boundaries of place where the inquiry and events take place” (p. 480). This commonplace recognizes that all events occur in some place. For narrative inquirers, “the specificity of location is crucial... Place may change as the inquiry delves into temporality” (p. 480). The qualities of place and the impact of places on lived and told experiences are crucial. Inquirers need to be attentive to how place shifts as stories unfold.

Connelly and Clandinin (2006), distinguish narrative inquiry from other forms of qualitative inquiry by their use of these three commonplaces. They allow narrative inquirers to understand their distinct place among a variety of qualitative research methodologies.

In nursing, Munhall (2007) described four existential life-worlds from which inquirers need to view and process phenomenological material to give it meaning (p. 194). She identified the first life-world as *spatiality*, referring to the space in which we are, our environment, which can assume different meanings for different experiences; *Corporeality* is the second life-world described by Munhall, which refers to the body that we inhabit and is also referred to as embodiment. Munhall encourages inquirers to contemplate the connectedness of embodiment with experience; the third life-world is identified as *temporality*, and is described as the time in which we are living. Munhall noted that our embodied bodies occupy a space and that space is located in time. Critical to the concept of temporality is history. We are located in a historical period that is influential in regard to our behavior, attitudes, beliefs, and where we are located (spatially). Finally, the life-world of *relationality* pertains to the world in which we find ourselves in relation to others.

Similarly, Charon (2006), invites healthcare professionals to examine five narrative features—temporality, singularity, causality/contingency, intersubjectivity, and ethicality. These narrative features will be discussed in greater detail in Chapter V: Constructing and Managing Narrative Text. All these complex conditions, according to Charon (2006) are “active aspects of routine clinical practice and are also bedrock aspects of narrative inquiry” (p. 39). Charon (2006) proposed that “narrative means might help bridge the chasms that exist between healthcare professionals and patients” (p. 39) by offering a common understanding and shared ways of knowing about illness experiences and that will improve effectiveness of care.

According to Charon (2006), healthcare professionals must understand these building blocks of stories in order to do their work. A symptom or disease is indeed an event befalling a character, sometimes caused by something unidentifiable, within a specific time and setting that has to be told by one to another from a particular point of view.

Healthcare professionals often fail to recognize explicitly the temporality within which lives, illness, and disease unfold; to grasp and value the singularity of each person and character; to face the search for causality and the acknowledgement of underlying contingency in life in general and in disease or illness in particular; and to fail to comprehend the intersubjectivity and ethical demands of telling one’s story and receiving the stories of others.

### Content, Structure, and Function of Narratives

Content, as well as the formal aspects of narrative structure, expresses the identity, perceptions, and values of the storyteller. According to sociolinguist

(Labov 1972, 1982; Labov & Waletzky, 1997), narratives have formal properties and each has a function. Labov proposed six common elements of narratives: an abstract (summary of the substance of the narrative), orientation (time, place, situation, participants), complicating action (sequence of events), evaluation (significance and meaning of the action, attitude of the narrator), resolution (what finally happened), and coda (returns the perspective to the present).

Structured analysis strategies, according to Tuval-Mashiach (1998) are based on consideration of narrative typology, progression of the narrative, and cohesion of the narrative. A favored typology includes the four principle narrative types: the romance (the protagonist struggles with but overcomes obstacles that impede her from reaching her goals); the comedy (the protagonist overcomes the hazards that threaten her); the tragedy (the protagonist defeated by the obstacles that impede her from reaching her goals) and the satire (provides a cynical perspective on social hegemony).

Narrative development of the plot over time also provides important information about how the storyteller views her journey through a particular event: Progressive narratives (a story that progresses steadily); Regressive narratives (there is a course of deterioration or decline) and Stable narratives (the plot is steady). These basic formats can be combined to construct more complex plots (Gergen, 1988).

Holloway and Freshwater (2007) summarized the functions of narratives for storytellers by stating that reflection on experience may:

1. Give meaning to and make sense of experience and emotions.
2. Help the narrator to interpret events.

3. Express, enhance or confirm the narrator's identity.
4. Segment and organize experience, actions and events.
5. Also provide a coherent whole of experience and thoughts.
6. Generate change in thinking through making explicit, and bring about adjustment to unalterable conditions.
7. Confirm group membership or group consciousness.
8. Attribute responsibility, blame, or praise to specific individuals.
9. Allow individuals to take control of their own story. (p. 21)

### Hermeneutic Influences and Narratives

Ricoeur's (1973, 1991, 1995) interpretive theory and ethical vision functioned as the theoretical source of inspiration in the interpretation of the stories of mothers' NICU experiences. A hermeneutic phenomenologic philosophy inspired by Ricoeur's interpretative theory will be used as a guide for analysis.

Patton (2002), noted that hermeneutics originated in the study of written text. Narrative analysis extends this idea of text to include in-depth interview transcripts, personal narratives, autoethnographies, family stories, suicide notes, graffiti, literary nonfiction, and life histories. Each of these forms of expression has the potential to reveal cultural and social and ethical patterns through the lens of individual experience (p. 115).

The hermeneutical perspective, with its emphasis on interpretation and context, informs narrative studies as do phenomenology's emphasis on understanding lived experience and perceptions of experience (Bochner, 2001). The "narrative turn" in qualitative research honors people's stories as sources of data that can stand on their own as pure descriptions of experience which is the

core of phenomenology (Bochner, 2001). Stories are analyzed for connections between the psychological, sociological, cultural, political, moral and dramatic dimensions of human experience (Patton, 2002 p. 115-116).

“The central idea of narrative analysis is that stories and narratives offer especially translucent windows into cultural and social meanings” (Patton, 2002, p. 116). In the more recent hermeneutic tradition, the text to be interpreted can be any written document and according to Ricoeur (1991), it is even possible to consider human actions as texts. Narrative is a hermeneutic project in itself because it is by narration that we structure our interpretations of the world. Narration is the core of understanding, which was the first interest of hermeneutics (Wilklund, Lindholm, & Lindström, 2002, p. 115).

According to Ricoeur, understanding must be conveyed through explanation. The experience of an individual cannot be conveyed in an immediate way, but is represented via symbols, metaphors and interpretations of written or spoken narratives (text). A written discourse is a dialectic between explanation and understanding and establishes the hermeneutic domain. The text contains a flood of meaning and has the ability, by its containing an intention, to shed new light on a person’s lived experience. There is a need for research in nursing to extend knowledge from an ethical platform, and in this work Ricoeur’s ethical vision—a wish for a good life with and for others in trustworthy institutions—will guide the interpretation process (Ricoeur, 1973, 1984, 1985, 1988).

My understanding of narrative methodology was enhanced by reading Layne’s biographical and autobiographical piece titled “*How’s the Baby Doing? Struggling with Narratives of Progress in a Neonatal Intensive Care Unit*”. In her

article, Layne describes the process of “knowledge-making” of one neonatal intensive care parent. In particular, she investigated the ways that narratives of linear progress informed her own efforts in understanding her son’s condition and future prospects. She explored how the discrepancy between narratives of linear progress and the complex and volatile condition of many premature and/or critically ill newborns is discursively managed in the neonatal intensive care unit using three common metaphors that describe an infant’s changing conditions in the NICU—*roller coaster*, *graduation*, and *course*.

Barthes (1977) suggests that narratives arise between our experience of the world and our efforts to describe that experience in language, narrative “ceaselessly substitutes meaning for the straightforward copy of the events recounted” (p. 79). And it would follow, according to White (1980), that “the absence of narrative capacity or a refusal of narrative indicates an absence or refusal of meaning itself” (White, 1980, p. 2). Psychologists have argued that the kinds of meanings people draw from significant turning points such as illness, tragedy, etc have profound implications for their overall adaptation and mental health (Taylor, 1983; Tedeschi & Calhoun, 1995; Vaillant, 1977). From this, it follows that as women encounter experiences related to pregnancy and childbirth, their personal meanings undergo transformation. Loss of a sense of meaning in life can have a negative effect on health and well being of the mother.

Taylor (1983) argued that when an individual has experienced a personally threatening event, the readjustment process focuses around three themes: a search for meaning in the experience, an attempt to regain mastery



over the event in particular and over one's life in general, and an effort to enhance one's self-esteem-to feel good despite the personal setback.

Taylor (1983) described meaning as an effort to understand the event: why it happened and what impact it has had. The search for meaning attempts to answer the question: "What is the significance of the event?" Meaning is exemplified, but not exclusively determined, by the results of an attributional search that answers the following questions, "What caused the event to happen?" and "What does my life mean now?"

Lack of a sense of meaning has been associated with negative effects to health and well-being which can cause a decline in mental health leading to psychopathology (Crossley, 2000). For a mother, delivering an ill infant represents a traumatic event for which they are poorly prepared. To date, the focus of scientific interests has been on maternal psychological stress responses, such as anxiety and depression, or on appropriate coping mechanisms, whereas scant attention has been paid to the traumatic aspect of the maternal experience and her search for meaning. Studies have shown that mothers of premature infants are significantly more anxious and depressed than mothers of term infants in the postpartal period (Callahan & Hynan, 2002; DeMier, Hynan, Harris, & Manniello, 1996).

Healthy People 2010 identified depression as 1 of 10 leading public health issues in the United States ([www.healthypeople.gov](http://www.healthypeople.gov)). Research shows that women are more at risk for depression while they are pregnant, and during the weeks and months following birth (U. S. Department of Health and Human Services (HRSA) web site).

How are the increased levels of anxiety and depression in mothers of sick and prematurely born infants related to the mothers search for meaning in the traumatic experience of bearing a sick baby? Crossley (2000) suggested, "traumatic events in a person's life can lead to a radical sense of disorientation and the breakdown of a coherent life story" (Crossley, 2000, p. 57). She continued, "the experience of mental illness has been characterized as amounting, at least in part, to suffering from an 'inchoherent story', an 'inadequate narrative account of oneself' or a 'life story gone awry'" (Howard, 1991; Polkinghorne, 1988; Showalter, 1997 as cited in Crossley, 2000, p. 57). If nurses can develop greater understanding into the lived experience of the NICU and the mother's ability to find meaning, they can use this knowledge to facilitate mothers in finding meaning and promoting well-being, even in the face of adversity. A worthwhile goal is to avoid psychopathologies associated with inability to find meaning and story traumatic events. Labov and Waletzky (1997) noted that "narrative is essentially a hermeneutic study, where continual engagement with the discourse as it was delivered gains entrance to the perspective of the speaker and the audience, tracing the transfer of information and experience in a way that deepens our own understanding of what language and social life are all about" (p. 1).

#### Narrative Continuity and Sense of Coherence

Narrative researchers have often asked, "Does life gain coherence and meaning through narratives?" Some researchers claim the answer is yes. The idea that individuals react differently to adverse conditions of experience, and that these reactions can affect their health and their well-being is firmly

rooted in the process of emplotment. According to Goldie (2004), "emplotment is an active process characterized by three features of narrative; coherence, meaningfulness, and emotional import" (pp.157-159).

The first characteristic feature of narrative is coherence. A coherence system is a "system of beliefs and relations between beliefs" (Linde, 1993, p. 163). Continuity is a form of coherence, especially related to narrative, because it operates in time, time being a basic constituent of narrative. Continuity is the chronological linkage between three temporal dimensions: past, present, and future that reveals causal connections in a way that would not be achieved by simply listing the events that transpired (Rimmon-Kenan, 2002).

Mattingly (1998) suggests that a coherent plot gives unity to an otherwise meaningless succession of one thing after another. According to Mattingly (1998), "to have a story at all is to have made a whole out of a succession of actions" (p. 46). This "making a whole" is also making meaning such that we can ask what the point or thought or moral of the story is (Ricoeur, 1984; White, 1980).

The second feature of narrative is meaningfulness. Goldie (2004), suggests that it is through emplotment that the narrator gives meaningfulness to the raw material by presenting what happened in a way that enables the listener of the story to find intelligible the thought, feelings, and actions of the protagonists who are part of, or internal to, the content of the narrative, and whose internal perspectives are presented in the narrative (p. 159).

The third characteristic feature of narrative described by Goldie (2004), is emotional import. "Emplotment gives emotional import to what happened. It

provides the narrators external perspective or emotional response to what happened, from the perspective of what the narrator now knows" (pp. 150-160).

In illness, trauma and turning points, however, the past, present, and future linkage, characteristic of both stories and "narrative identity," is destabilized or disrupted. And it is the implicit or explicit assumptions of continuity that underlies the experiences of disruption as one of the traumatic aspects of illness (Rimmon-Kenan, 2002, p. 12).

### Narrative Discontinuity and Disruption

What does it mean when a story is not coherent? Stories that lack coherence do not have a clear beginning, middle, or ending. They may be muddled or unfinished stories. What does narrative coherence or lack of coherence suggest about life as experienced? Some authors (Mattingly, 1998; Rimmon-Kenan, 2002; Wilkan, 1995) have argued that stories are not nearly as coherent as narrative scholars claim them to be.

Some theorists such as Wilkan (1995) have challenged the popular view that coherence is the main value of narrative. Mattingly (1998) also claims that, "If narrative offers an intimate relation to lived experience, the dominant formal feature that connects the two is not narrative *coherence* but narrative *drama*. Humans follow a narrative in suspense, always reminded of the fragility of events, for things might have turned out differently" (p. 154).

Garro and Mattingly (2000) argued, "that life is never merely the enactment of prior narrative texts. Stories told about events necessarily "fictionalize" them by providing a form and meaning lacking when they were lived out" (p. 269). According to Garro and Mattingly, attention to narrative forces us to

confront the problem of meaning and the human affinity to endow experience with meaning.

Rimmon-Kenan (2002), argued that narrative continuity is an illusion, perhaps disruption is the rule, rather than the exception in narratives of illness. Disruptions are often described as turning points, disconnections, gaps, feelings of being ruptured or shattered. Disruptions often show up as narrative fragments with temporal irregularities adding to perplexity and confusion.

However, Rimmon-Kenan (2002) also noted that discontinuities in illness are not fully fragmentary. "Disruption is often countered by signposts, situating the reader in place and time" (p. 21). Most illness narratives are told in retrospect, and "narrating after the event tends to be more coherent than telling during the suffering" (p. 22). "Coherence is likely to be interpreted as a sign of control or mastery, and readers usually prefer stories of triumph" (p. 22). Stories that are disintegrated and fragmented also "upset the cure-promising authority of healthcare institutions" (p. 22), thus provoking anxiety and this may have led to the slant toward narrative coherence.

The point taken from Rimmon-Kenan's work is that the narrative researcher should be aware of the narrative structuring process, in which ill subjects, and their significant others tell their stories. They may contain phases of disintegration and fragmentation as well as moments of pulling toward continuity and coherence, and these may even be simultaneous (Rimmon-Kenan, 2002).

Understanding theoretical and methodological concepts as they relate to narrative inquiry can provide the researcher with guidance when attempting to answer the following questions about mothers' narratives:

1. How do mothers bridge the gap through narratives?
2. How do their narratives comply with or resist the dominant cultural norms?
3. How did mothers show fear, sorrow, depression, anger?
4. How did mothers show control, activity, progress, master, triumph?
5. Do mothers' narratives of their infant's illness align with the past, present or future?
6. Do the narratives represent progression, regression, stability, or various combinations among them?
7. Is continuity/disruption the rule, rather than the exception?

### Silence

But what does the narrative researcher make of silence? According to Wilkan (1995), "silence can speak, sometimes louder than words" (p. 264). Wilkan (1995) insists that it is important to distinguish narratives and silence as two distinctive modes of expression. "Silence cannot convey the elaborate particulars that define narrative, and, conversely, narrative *forces* you to engage in particulars of which silence relieves you" (p. 264).

Narrative is the favored medium of researchers because it conveys feelings and thoughts. Silence receives scant attention but the two modes of expression are interdependent. Silence is closely linked to another and different mode of expression, action (p. 265). Narrative and silence offer individuals different opportunities to craft selves within a framework of meanings. Wilkan (1995) suggests that the academic obsession with words must not make us insensitive to everything that is *not* said: an analysis of what is unspoken and unspeakable can afford privileged insight into life experiences in the most trying of times (Wilkan, 1995, p. 265).

Poirier and Ayres (1997) proposed that narrative inquiry entails “overreading,” a sensitivity to unspoken or indirect statements, which is central to interpretation. In particular, the authors provide narrative researchers with literary tools to help them attend to inconsistencies, endings, repetitions and silence.

Narrative inconsistencies, as described by Poirier and Ayres, signal points of confusion, uncertainty, or conflicting emotions in the narrator. They say, “pay particular attention” (p. 552). Narrative repetition is described by Brooks (1992) as the movement from passivity to mastery... of what one must in fact endure” (p. 98). Repetition is a fight for control. There are unspoken meanings in repetitions.

Attending to narrative endings often focuses on the future and gives meaning to current events. We read narratives, anticipating the structural power of endings that will retrospectively give them order and significance of plot. But what of the storytellers who cannot tell the end of their tale? This may be the case with a mother whose child is born with a disability or requires hospice care at the end of life. Wilkan (2000) notes that to understand lived experience, we need narratives, stories unfinished, muddled, in-the-midst-of-experiences whose only certainties are the beginnings or turning points and not a clue of how it would end (p. 234).

Silences are another narrative element used when the storyteller profoundly fears confronting the knowledge of the experience. The storyteller may change the subject, withdraw from talking about the experience, move to another subject or lose their place in the storytelling. Evasions allow the storyteller to remain silent about particularly painful memories or feelings. Wilkan

(2000) asked, "Why does silence derive short shift? Some reasons are notions of honor and shame. Narrative is simply not an option for many people in their most trying life circumstances" (p. 232). Wilkan (2000) does not advocate imposition or intrusion, by the narrative researcher, but instead he suggests a better and sharper exploration of the counterplay between silence and narrative as a way to enhance our understanding of lived predicaments.

Poirier and Ayres (1997) warn that narrative researchers should be aware of and utilize the tools of "overreading" in interviews with caution. Secrets, repetition, and silences may protect the participant from emotions or memories too painful to recall. Poirier and Ayres (1997) provide the following four guidelines that the narrative interviewer should keep in mind during the interview process: First, where the researcher notes inconsistencies, repetitions, and omissions, they can, with relative assurance, identify the interviewee's confusion about, discomfort with, or avoidance of, a subject (p. 556).

Second, interpreting why this confusion, discomfort, or avoidance exists should be undertaken cautiously, if at all. Poirier and Ayres (1997) suggest that as researchers, we should refrain from imputing too-distant causes and should rest with identifying unanswered questions out of respect for the participant and possible recognition of the impossibility of absolute certainty. Recognizing and honoring the silences and contradictions in the research interview acknowledges the vulnerability of both the teller and the reader of a story (pp. 556-557).

Third, an effort should be made to change names, places, times, and as many identifying details of families without destroying the narrative information which may reveal inconsistencies, repetitions, and silences in their stories to



provide the participant with anonymity. And fourth, when noting competing and potentially upsetting interpretations, always honor the teller's sincerity and fragility (p. 557).

Silence, repetition, and endings are tools that structure, lead (or mislead), and give meaning—though not necessarily the same meanings—to both the teller and the listener. Paying attention to these structures will bring the researcher one step closer to the complexity of the teller's life experiences (Poirier & Ayres, 1997).

In the same vein, Rogers (2007) distinguished four ways of identifying and interpreting languages of the unsayable including (a) a language of negation, (b) a language of revision, (c) a language of smokescreen and evasion, and (d) a language of silence (p. 113).

Josselson & Lieblich (1999) noted that an "analysis that considers only the spoken, no matter how complex, risks overlooking an essential aspect of expression and meaning" (p. 80). There is a wide array of theoretical and methodological perspectives for narrative research. Many of the approaches overlap with others or blend approaches. For this reason, narrative research has been described as a "blurred genre" (Geertz, 1983) or boundary phenomenon.

Langellier (1989) differentiated among different theoretical approaches to personal narratives as : story-text, storytelling performance, conversational interaction, social process, and political praxis. Mishler (1995) proposed a typology of models of narrative analysis: reference and temporal order, textual coherence and structure, narrative functions (p. 90).

## Identity and Narratives

People's lives are not stories, but we do tend to understand them in that way. Polkinghorne (1988) proposed that "the self is a concept defined as the expressive process of human existence, whose form is narrativity" (p. 151). "Narrative presupposes and draws on the human competence to understand action. Self identity becomes linked to a person's life story, which connects up the actions into an integrating plot" (Polkinghorne, 1988, p. 151).

Mishler (1986a) proposed two notions about a story. First, that whatever else the story is about, it is also a form of self-representation in which the teller is claiming a particular kind of self-identity. Analysis can be directed to the content of this self-identity and to the various episodes and themes that the interviewees selected in support of their identity and to the cultural values presupposed by it. Second, because "everything said functions to express, confirm, and validate this claimed identity," (p. 243) the researcher can search for statement and references related to the teller's identity throughout the account

Self-representation is a privileged symbolic feature of narratives since it articulates the moral position that the speaker has taken on the turning point and its consequences. How listeners respond to the story determines how they respond to the storyteller, and through the account an ethical relationship has been proposed, if not established (Gubrium & Holstein, 2001, p. 723).

The relationship at the heart of narratives is a search for mutual understanding. A narrative researcher can make visible neither the limitations nor the critical capacities of the narrative's meanings without delving into the text of

the interview and beginning a process of dialogue with the narrator (Josselson, Lieblich, & McAdams, 2007).

A number of theorists view the construction of personal narrative as central to the development of a sense of one's self, of an identity. Sarbin (1986), for example, proposed that "Human beings think, perceive, imagine, and make moral choices according to narrative structure" (p. 8). And MacIntyre (1984) has claimed that people's lives are stories because "action itself has a basically historical character" (p. 212). MacIntyre further claims that a self is "the subject of a narrative that runs from one's birth to one's death," and identifies the meaningfulness of that narrative/life with "its movement toward a climax or telos" (p. 217), a structure that he described as a quest. Hardy (1968) has written that "we dream in narrative, day-dream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, construct, gossip, learn, hate and love by narrative" (p. 5).

#### Motherhood, Feminism and Narrative Inquiry

The novelist Smiley (1998) suggests that "motherhood is the most public of personal conditions" (p. 39). This may be the case, particularly, when the newborn infant requires care in the NICU. Mothers are often bombarded with advice from doctors, nurses, family, friends, and strangers—much unsolicited and most of it contradictory—about how to be a good mother. Every action is morally freighted: was prenatal care appropriate, limited or lacking? Will the mother be bottle feeding or breastfeeding? Will the mother deliver naturally or with the assistance of a pain relieving epidural? Will the mother be consuming or refusing painkilling drugs during and following childbirth?

Even the most mundane actions carry moral weight, and since mothering is usually a round-the-clock, day-by-day undertaking, it can pervade a woman's daily round of activities. Even when she is not with the infant, tending to their needs, a mother often has her child(ren) in mind.

What often gets lost in the midst of these ongoing debates is the realities of mothers' lives, indeed, the incredibly diverse realities of mothers' needs, struggles, joys, and hopes and dreams for their children and for themselves. What is it about narratives that can address women's experiences in a meaningful way? And, is narrative research feminist research?

First, it is important to mention that there is no one kind of feminist research or method. In defining feminist research, Brayton (1997) discovered that what makes feminist research feminist are the motives, concerns and knowledge brought to the research process. Feminist's beliefs and concerns act as the guiding framework to the research process.

Brayton (1997) defined three features of feminist research. The first feature described by Brayton is that the unequal power relationship between researcher and the participant is restructured to validate the perspective of the participant, this entails involving the participants at all levels of the research process. Feminist research takes women's situations, concerns, experiences and perspectives as the basis for research. It embodies women's experiences in the social world from their own interpretation and using their language. Issues that are important to women then become the starting point for doing research. Research has meaning in the world, and feminist research must attend to the

meanings women give to their experiences, what they identify as being topics that concern them.

The second feature noted by Brayton (1997) is that feminist research is politically motivated and has a major role in changing social inequality. It is important in feminist research to ensure the accuracy of the research in depicting women's lives and experiences. This can be accomplished by taking research findings back to participants for verification since they are the experts and owners of their own personal experiences. Feminist research must not be abstract and removed from the subject of investigation but instead must have a commitment to working toward societal change, in the form of recommendations for policy change to improve the conditions and lived experiences of and for women. Feminist research also has the capacity of raising the consciousness of individuals caring for women in the healthcare setting.

The third feature of feminist research noted by Brayton (1997) is that feminist research recognizes the researcher as part of the research process and the researcher brings his or her own experiences and history into the role of researcher and the research process. Brayton stated that it is important for the researcher to identify his or her own social location in order to address biases. She also suggests that feminist researchers critically examine their own framework of understanding. This is important because the choices being made by the researcher are shaped and motivated by his or her social location, from the choice of the research topic to the decisions on how to present the findings.

Feminists research is not about valuing qualitative research over quantitative research; rather it is concerned with allowing feminist beliefs and

concerns to guide and direct choices and decisions. The use of narrative inquiry as feminist inquiry has great potential to capture the interpersonal and social aspects of women's lives. Narratives of women can offer complexity and multifomity to understanding health experiences unique to women including, pregnancy, birth, and mothering (Brayton, 1997).

Narrative inquiry and feminist theory allows a space for mothers' voices to be heard. Both value considered experience as knowledge (Belenky, Clinchy, Goldberger, & Tarule, 1986). Both emphasize interconnections and interpersonal aspect of meaning and care. Both emphasize the differences among people rather than making abstract generalizations about human nature. Both employ the use of language and esthetic experience to express not only the course of events as experienced by the individual but the meaning of an event. Both are concerned about imbalances of power in regard gender, class, race in the study of women.

Allowing mothers an opportunity to be heard opens the door for stories that resist the medicalized story of their experience (Layne, 2003; Nelson, 2001). Counterstories, according to Nelson (2001), may serve as a tool for re-identifying those whose identities have been defined by those with the power to speak for them and to constrain the scope of their actions (p.154).

However, Mot and Condor (1997) argued that narratives are "not always subversive or transformative of existing power differentials in society" (p. 64). People might not be conscious of the aspect of life histories they share with others, and although narratives are important, they do not provide a simple panacea. Narratives provide insight into individual lives but provide no guarantee

of resolving inequalities; in fact, they may even contribute to, rather than undermine, societal inequalities. Atkinson (1997) noted “we are as likely to be shackled by the stories we tell (or that are culturally available for our telling) as we are by the form of oppression they might seek to reveal. Narrative is not always emancipatory. All narratives will to some extent maintain and reflect the dominant threads of the social fabric, and therefore all research is in danger of supporting and reproducing the existing power differentials. With that in mind, the aim of this narrative study is to provide mothers’ stories primacy rather than the medicalized story without exploiting the individuals who have consented to and contributed detailed biographical accounts of their lives and experiences.

#### Ethics and Narrative

There has been an ongoing debate in bioethics between principlism on one side and narrativist on the other. Childress has argued that the debate over narratives (a contextual approach) and principles (moral norms) has been misplaced. Childress does not conceive ethics to be exclusively one or the other, he argues that a relationship exist between the two (Childress, 1997).

Many authors have argued that narratives are an essential supplement to Beauchamp and Childress’s (2001) principles of biomedical ethics (Arras, 1997; Charon; 1994; Walker, 2007). “Narratives situate moral problems in actual human experiences” (Brody, 2003, p.181). Childress (1997) has argued, “If we start with either norms or narratives, we are driven to the other” (Childress 1997, p. 268). Brody (2003) has noted that a “narrative conception of a lived life is essential for making sense of the ethical concepts of virtue and character” (p. 181).

Walker (2007) elaborated on the idea that a story is the basic form of representation for moral concerns. She stated that "one's moral life takes the form of an unfolding narrative... a story is the basic form of representation for moral problems. Walker suggests that most of the moral work will be done by a set of three intertwined narratives-narrative of relationship, identity, and value (p. 116).

Walker (2007) defined "*narrative of relationship* as a story of the relationship's acquired content and developed expectations, its basis and type of trust, and its possibilities for continuation" (p. 117). These narratives describe, "How we got here together" (p. 117). Consider for example, a relative stranger to the NICU, a mother enters in need of assistance, where the needs and interests are entirely obvious or where the situation is urgent (a premature or ill child), there is no antecedent story of relationship to explore, and the imaginable interpersonal sequels are typically limited as well. These may be very short stories of our moral lives, but they still may end more or less credibly, and their matter and implications may be significant parts of larger stories that reveal how well or badly we live or how easily we can make moral sense of ourselves (p.117).

Walker (2007) described "*narratives of moral identity* as a persistent history of valuation that can be seen in a good deal of what a person cares for, responds to, and takes care of" (p.118). These narratives describe, "Who I am" (or who we are) (p. 118). Moral identity shapes and controls our history of responses to others. It is important to understand a person's values because



there are many specific versions of moral excellence and a better understanding of values lets others know where we stand and what we stand for.

The third kind of narrative that Walker (2007) described, is the "*narrative of moral values*". This kind of narrative, according to Walker, describes "What this means. Narratives of moral values involves a history of moral concepts that individuals have acquired, refined, revised, displaced, and replaced, both by individuals and within some communities of shared understanding. These types of narratives are essential to keeping justification coherent within and between us" (119).

Walker (2007) explained, narrative understanding of the moral construction (and reconstruction) of lives is central to understanding how responsibilities are kept coherent and sustainable over substantial stretches of lives that, in important—but not imperial—ways, remain people's own.

Recent research on illness narratives has emphasized the moral qualities of the experience of illness and disability (Becker, 1997; Frank, 1995; Gray, 2001; Hyden, 1995; Radley, 1999; Smithbattle, 1994; Williams, 1993). As previously noted, illness narratives have a strong moral component that is the result of individuals' attempts to reconcile the distress caused by their sense of difference due to their illness and their desire for normality.

Delivering a sick baby presents especially formidable challenges to women because its symptoms are disruptive to the most basic of aspects of daily family life. Accordingly, many women who are unable to carry their pregnancy to term or who deliver anything except a normal healthy newborn may view

themselves to be abnormal and experience severe distress as they struggle to reconcile their experience with their desire to be a good, if not perfect mother.

Although the concept of the “perfect mother” is inherently problematic, it nonetheless represents an important working concept for the women suffering from the NICU experience as well as the providers of healthcare in the NICU. Such providers- in this case nursing, nurse practitioners, obstetricians, pediatricians, and neonatologists- have concepts of *family normality* and *mothering normality* that provide the basis for a co-authored narrative of normal family life. Such a narrative provides the basis for a moral resolution of the women’s experience of birth. Not everyone shares the same narrative. The experience of bearing an infant prematurely or with health problems must be placed in the context of each woman’s life and reconciled to her central values. In some cases, this can be accomplished in the context of narratives co-authored with healthcare providers (nurses) that reflect professional ideas of normality.

There has been reluctance by health care providers to address the inescapable moral and existential dimensions that mothers encounter within and beyond the NICU. Layne (2003) observed that the preferred American narrative structure is one of success, progress and faith. This narrative structure stems in part from our belief in science and technologies’ ability to provide a cultural and scientific “fix”. “Fetuses that don’t develop properly and babies that [are ill] or die challenge cherished narratives about the natural course of individual development and, given its own linear progress, our assumptions about biomedicine’s ability to assure that pregnancies and babies stay on this expected path” (Layne, 2003, p. 68).

Layne (2003) noted that there is a culture of silence surrounding bereaved mothers whose pregnancies were cut short by miscarriage, premature birth, birth defects (physical and mental abnormalities) and infant loss. In this study, I will add *threatened loss*, a further source of bereavement because NICU infants are in a vulnerable state due to prematurity and/or disability and they often experience episodes in their illness course that threaten their life on a moment to moment interval causing extreme anxiety for the mother and family.

Loss including *threatened loss* can endanger the mother's basic beliefs about self and life in general. One example of this situation is when a premature infant experiences what is known in the NICU as apnea & bradycardia episodes that require continuous monitoring by the nursing staff, as well as interventions ranging from mild tactile stimulation to CPR for the infant to recover. These episodes are often witnessed by the mother while she visits with her infant in the NICU, and may represent one aspect of *threatened loss* (Sarah Steen Lauterbach, personal communication, 2007).

Hester (2001) contends, "the more complex and threatening the experience of illness for the patient [and in this case the mother], the more it tears at the fabric of the person's life. And conversely, *the more an ailment tears at the fabric of our relationships, the more severely it is experienced* [italicized in original]" (p. 70). Hester continues, "This notion is important in elevating the building of [healthcare] community and preservation of the fabric of patient's relationships to a position of primacy within health care's mission" (p. 74).

Individuals in our society long for stories of success and progress. According to Frank (1995), they too often turn away from the 'difficult duties as

human beings to listen to the voices of those who suffer' (p. 23). Instead attention is more often focused on advancing technological and scientific aspects of care. Frank (1995) argued, that ethicists and healthcare practitioners must move in the direction of thinking *with* stories. "Thinking with stories is the basis of narrative ethics" (p. 158).

For Frank (1995) "the goal of narrative is to enhance [healthcare providers] hearing of stories that might not otherwise be heard or might be treated as "just" conversational with no clinical or ethical import" (p. 156). According to Frank (1995), "hearing stories of experience opens up moral dimensions of peoples lives" (p. 156). As Frank (1995) observed, one of the main challenges of illness is to construct a story that can turn mere existence and stigmatization into a meaningful social, moral, and self-validating life. Brody (2003) identified two ways that narrative and ethics can intersect:

First, he noted that "narrative ethics" is the claim that even when one is using principles or other general norms, one is engaged in an activity that relies on or engages narrative in some way and second, narrative ethics is the claim that one need not use principles or other general moral norms, but can gain ethical knowledge and provide ethical justification directly through and from narratives. (Brody, 2003, p. 175)

As previously noted, however illness narratives also contain aspects of resistance to normalizing ideologies (Nelson, 2001). One example noted by Nelson (2001), is the idealized standard of primary child-care responsibility being assigned to women, regardless of their physical or mental well-being following childbirth.

Polyanyi (1985) proposed that the aim of telling stories in conversation is “to make a point—to transmit a message, often some sort of moral evaluation or critical judgment—about the world the teller shares with other people” (p. 187). More often than not, the moral of a story concerns things turning out differently than the characters anticipated. That is, a collision between expectations and experience (what, actually happened) gives narrative its drama (Mattingly, 1998, p. 157).

According to Frank (2004) illness is an inherently moral experience, as it seeks to sort out what was lost, gained, and preserved. Frank (2004) suggests that a moral decision is any action that a person understands as affecting her or his progress toward finding or achieving the unique point-or points —of her or his life.

Frank (2004) noted that illness often serves as an occasion to offer testimony about a suffering that society too often ignores, compartmentalizes, and diminishes. Narratives seem necessary and natural media for people who value not the philosophically “examined life” but rather the “experienced life,” (p. 180). Narratives explore what is “better or worse,” at least in the life of the narrator. Frank proposed that “the bridge between universal ethics and one’s own little voice is dialogue” (p. 182).

### Helping Relationships and Narratives

According to Watson, entering into a relationship with the other requires sensitivity to being human, and in facing our own and another’s humanity in reaching out to other, is itself, a healing act. It takes place in any caring moment

where there is an authentic human-to-human encounter... face-to-face (Watson, 1999; Watson, 2003).

Mattingly noted that good clinical practice depends upon care provider's recognizing that every new patient brings a new situation, not simply a replica of other patients. Narrative inquiry, acknowledges the encounter with the other as an event of particularity, wherein hurt, vulnerability, pain, grief and suffering elicits a human-to-human response and this response is the core of clinical knowledge and care practices (Charon, 2006; Mattingly & Garro, 2000 ).

### Nursing Practice and Narratives

Nursing in the Neonatal Intensive Care Unit is a "ritual of the everyday" played out in the clinical world, "the world of the not everyday" Mattingly, 1998, p. 165.

Nurses are constantly confronted with stories during their encounters with patients. The implications of the understanding of narratives are important for this work. Stories have the potential to illuminate the NICU mothers' shattered world. However, in order to respect mothers' stories, nurses must be committed to active, respectful, confirming listening. Listening helps us as healthcare providers to determine what the mothers' wishes, choices and actions really are. Listening is morally important to honor persons and their stories. Watson (1985) noted that fostering the development of helping-trust relationships is a basic carative factor in nursing. Therefore, basic nursing skills must incorporate awareness, empathy and warmth, failing to respond and listen to mother's stories can lead to potentially harmful and even destructive relationships between nurse and mother (p. 39). In this case, to better understand the mother's conceptions of a good life and/or death for her child requires an approach to clinical practice, research and education that helps us to see what went wrong or right from the standpoint of

care. Listening then not only promotes the expression of positive feelings but also the acceptance of expressions of negative feelings in self and others. Fostering this type of relationship allows for exploration, understanding and constructive action to take place which can often lead to improved care.

### Summary

This study is framed by the conceptual and philosophical views of Watson's theory of nursing as the science of caring and her views have informed this narrative inquiry. Watson's theory of nursing science and narrative inquiry are compatible in that both promote wholeness, both examine the total person in context, both cultivate sensitivity to one's self and to others, both promote the acceptance of the expression of positive and negative feelings, the allowance for existential–phenomenological forces, both are grounded on a set of universal human values.

Narrative inquiry does not lead to conclusions about certainties in the world, but to the varying perspectives that can be constructed to make experience comprehensible (Brunner, 1986a, p. 37) Narratives may also assist healthcare professionals to:

1. Better understand the narratives embedded in clinical practice.
2. Be open to different kinds of knowledge needed to practice effectively as a nurse or physician, by what some call making the familiar "strange".
3. Discover important ways in which narrative provides an avenue of inquiry to deepen knowledge, for example, to uncover new ways of interpreting and understanding one's patients' ways of knowing and making meaning—otherwise hidden from view.
4. Heighten their awareness of the centrality of interpretation and meaning in one's own professional development as well as in one's discipline.

Ellis and Bochner (2003) note that “narrative inquiry provokes readers to broaden their horizons, reflect critically on their own experience, enter empathetically into worlds of experience different from their own, and actively engage in dialogue regarding the social and moral implication of different perspectives and standpoints encountered” (p. 225).

“A narrative framework certainly affords nurses special access to the human experience of time, order, change, and it obligates us to listen to the human impulse to tell tales” (Sandelowski 1991, p. 165). Research that is motivated by the need to understand and appreciate the world of meanings as represented in stories requires a methodology that is open to uncertainty. Narrative research also demands an openness to what may be learned from differing methodologies including aesthetic expressions including poetry, literature and art, while in pursuit of individual goals for a narrative study. Clearly, the diversity of narrative strategies offers a more comprehensive and deeper understanding of both how narratives work and of the work they do.

Narrative and esthetic dimensions of caring are integral to pluralistic inquiry which incorporates all sensibilities, including bodily reactions, emotions, feelings, intuitions, cognitions and aesthetic sensibilities. As Zaner (2004) noted “we tell stories because it’s what we have to do. It’s what we are about. We care for one another with the stories we place in each other’s memory; they are our food for thought, and life” (p. 15).



## CHAPTER IV

### PLAN OF INQUIRY (METHODOLOGY)

#### Introduction

This chapter provides a review of research questions and an overview of the methodological approach and procedural steps that were chosen to execute this study. I also described assumptions, role of the researcher, role of participants, ethics and the research relationship including methods to protect human subjects. The study design is discussed, including research setting, sample selection and recruitment strategies, and the timing of the study and techniques used to elicit stories in interviews. Details are provided about data sources including stories collected during narrative interviews and stories told by mothers about artifacts collected during their NICU course. Data collection strategies are defined, and data analysis strategies used to answer each of the research questions is discussed. There is also a brief discussion about how study results will be disseminated. In this chapter, my intentions were to maintain some balance between research and therapeutic intentions. I wanted to negotiate a plan that was both rigorous and open ended, allowing for some improvisation during the study evolution.

#### Review of Research Questions

1. What core narratives are told by mothers who have experienced having a baby in the neonatal intensive care unit (NICU)?
2. What do the stories reveal about mothers' search for meaning in the NICU experience?
3. What moral concerns are revealed in mothers' stories?

4. How might mothers' stories be viewed to improve care providers understanding of what is most common, most taken-for-granted and what concerns mothers' most so that quality care can then be provided?

#### Identification of Assumptions

According to Clandinin, Pusher, and Orr (2007), narrative inquiry is a dynamic process founded on a set of epistemological and ontological assumptions which are at play from the first narrative beginnings of a research puzzle through the representation and judgment of the narrative inquiry in research text. Narrative inquiry is supported by the epistemological assumption that we as human beings are storytelling animals and that we naturally construct stories out of cultural life in an effort to make sense of random experiences (Polkinghorne, 1988). Narrative inquiry also rests on the philosophical assumptions of interpretivism (Dodge, Ospina, & Foldy, 2005; Smith, 1989).

The turn to narrative represents a paradigm shift from doing research that aims to explain and predict events and behavior using laws of statistical probability to generalize causal relationships. Ospina and Dodge (2005) noted that interpretive researchers, on the other hand, aim to understand intention and action rather than just explain behavior. These two different modes of research according to the authors are based on two fundamentally different ways of seeing and therefore different methods and criteria for quality. Narrative directs attention to questions about what it means to interpret and experience the lived world (rather than explain or predict it); both from the perspective of scholars and the people they study. The interpretive mode of seeing—and thus knowing—can only

happen from inside the world, and it is always bridged by conversation. (p. 146)

Shank (2002) used the metaphor of the lantern to describe this way of seeing. The lantern brings clarity to dark places, it illuminates and provides insights, allowing observer to discover and reconcile meanings where it was not clearly understood before. This mode of research assumes that meaning can be better unveiled and understood in experience and through practice, and that it is mediated through stories, thus giving preference to interpretation.

Four foundational assumptions of narrative inquiry guided the current study: First, narratives are a median of expression and narratives convey meanings about lived experience. Active subjects construct narratives that are particular, personal and contextual in time and place. Narrative inquiry is concerned with understanding the individuals intentions, beliefs, values, and emotions that reflect situated social reality rather than an "objective reality" (Dodge, Ospina, & Foldy, 2005; Riessman, 2002).

Second, narratives carry practical knowledge that individuals have gained through their experiences. Polkinghorne (1988) noted,

Narrative is the fundamental scheme for linking individual human actions and events into interrelated aspects of an understandable composite... a meaning structure that organizes events and human actions into a whole, thereby attributing significance to individual actions and events according to their effect on the whole. (pp.13-14)

This view emphasizes the potential of storytelling to generate understanding about experience that is perspectival, the value of stories and the importance of crafting and telling stories from experience (Bruner, 1986). Narrative researchers

value a variety of ways of knowing and questioning of what counts as knowledge and these ways of knowing contribute both to our knowing and our being known (Pinnegar and Daynes, 2007, p. 30). Stories are told from a point of view but also situates that view in a particular social, cultural, moral or political context. The context then in turn assists the researcher to interpret the story and understand its meaning (Kramp, 2004, p.109). Interpretations, however, are partial, alternative truths that aim for believability, not certitude, for understanding rather than control. Therefore, there is no one truth but rather a range of interpretations as we define our stories.

Third, narratives are constitutive, meaning they are shaped by individuals for their own purposes, but at the same time, they are forces that shape human beings and help give them meaning to the social worlds they inhabit (Gergen, 1985). This view emphasizes that individuals are influenced by historical and institutional contexts and meanings. Understanding narratives in this way helps the researcher to attain a deeper understanding of social practices, organizations, institutions, and/or social systems. (Dodge, Ospina and Foldy, 2005; Josselson and Lieblich, 1999).

Fourth, narrative inquiry distinguishes the complexity of the individual, local, and particular and provides a surer basis for understanding our relationships and interactions with other humans (Pinnegar and Daynes, 2007, p. 30). Narrative inquiry yields a way of coming to understand by being open to the stories individuals tell and how they themselves construct their stories and, therefore themselves.

The four assumptions just described helped to guide the current study. Because maternal NICU experience is the object of this study, narrative inquiry is an appropriate research method. As a research approach, narrative inquiry offers an effective way to undertake the systematic study of maternal NICU experiences and meaning. Stories preserve memories, connect us with our past and present, and assist us to envision the future. Narrative inquiry has the power and the potential to reveal these individuals in all their complexity and uniqueness. "The principle attraction of narrative as method is its capacity to render life experiences, both personal and social, in relevant and meaningful ways" (Connelly & Clandinin, 1990).

#### Role of Researcher

As the researcher, I was the primary investigator responsible for gathering interview data from participants. The role of the qualitative researcher demands a presence, an attention to detail, and a powerful use of the researcher's own mind and body of analysis and interpretation of the data (Janesick, 2003 p. 63). Kvale (1996) has written extensively on qualitative research and he provides new interview researchers with practical guidelines for "how to do" research interviews. He noted that "three ethical aspects of the researcher's role concern scientific responsibility, relation to subjects and researcher independence" (Kvale, 1996, p. 118). Thus, the researcher is responsible for conducting research projects that yield knowledge worth knowing and that demonstrate validity and credibility.

The narrative researcher is also responsible for establishing a relationship of trust with the participant. Since narrative studies are based on real lives of

people converting what was once private into public knowledge, it can violate privacy, and can cause mental and social hurt and harm if we are not careful. Therefore, the narrative researcher needs to create an environment open to dialogue with participants co-creating what should be published and in what manner private lives should be revealed in the public arena. Narrative researchers need to remember that "we hold the meaning of people's lives in our hands" (Bar-On, 1996, p. 20).

Researcher independence is the acknowledgment of ownership of research choices, decisions and thoughts as well as one's own biases and prejudices. One way to account for ownership is to provide an explanation of the hidden thinking that underlies the study. Attention is paid to how aspects of the researcher's background influences their analysis. It is important for researchers to make note of their own reactions to the data. They have to remind themselves to back off and try to understand and to empathize with others regardless of their own personal feelings. Strong feelings, both positive and negative, should signal the researcher to reflect on what is going on, and should remind us that there are reasons why individuals act as they do, just as there are reasons individuals react as they do (Anderson, 2003; Kvale, 1996).

#### Interviewee as Participant

The use of narrative inquiry as an approach to nursing research, education and practice allows nursing students and practitioners to listen to participants' stories of experience as he or she understands them. In the present study, the approach allowed the researcher to attend to the stories that mothers told during narrative interviews about their NICU experiences. The approach also

allowed for including stories that mothers told about artifacts collected during their experiences in the NICU, including family photographs, memory books, journals, etc. These artifacts were viewed as integral and not peripheral to mothers' stories.

The relationship of the participant to researcher required a relationship of trust and the two developed a sensitivity toward each other and fostered an I-and-thou relationship (Buber, 1970) that allowed and promoted the humanity of both researcher and participant. A trust relationship generates reciprocity.

Reciprocity was important for research purposes: in collaboration, researcher and participants created narrative meaning. This interpersonal dynamic required the researcher to be a good container, that is, the researcher was able to listen empathetically without judgment, feeling from within the participant's emotional space.

Participants were asked to read through transcribed interviews and to make comments, clarifying what was said and contributing to credibility of data collected. Participants were asked to make comments for clarification to help the researcher better understand the text. Mishler noted, "If we wish to hear respondents' stories, then we must invite them into our work as collaborators, sharing control with them, so that together we try to understand what their stories are about" (Mishler, 1986b, p. 249).

#### Protection of Human Participants

An interview inquiry is a moral enterprise. Ethical dilemmas are endemic in all research; however interactive and relational research such as narrative inquiry intensifies the concerns. Therefore this study acknowledged and followed the

following guidelines for ethical conduct in narrative research (Josselson, 2007; Kvale, 1996; Munhall, 2007; Smythe & Murray, 2000).

#### *Institutional Review Board Approval*

In narrative research, guidelines need to be in place to protect human subjects. The personal interaction in the interview affects the participant, and the knowledge produced by the interview affects our understanding of the human situation. Therefore, ethical approval was obtained from the participating hospital institutional review board (IRB) and the University of Southern Mississippi IRB prior to beginning the study (see Appendix A ).

#### *Research Preparation*

I am a neonatal nurse practitioner with 20 years experience in working with mothers and neonates in the NICU. I have completed courses in qualitative research and attended The University of North Carolina Chapel Hill Summer Qualitative Research Institute led by Margarete Sandelowski on qualitative research interviewing and methodological approaches in qualitative research. I have also taken an oral history course with a focus on obtaining life narratives, including interview techniques, the importance of consenting participants and the need for constant monitoring of vulnerability concerning the subjects' wellbeing.

Harm to participants may not always be evident to the researcher, and participants need to have access to professionals who can meet the needs when the researcher is unaware of them or unable to do so (Gottlieb & Lasser, 2001). As a newcomer to qualitative research, I drew on the knowledge of experienced individuals from my dissertation committee as well as clinical colleagues throughout the research process (see Appendix L).



### *Avoiding conflict of interest*

One way to avoid conflict of interest was to allow disinterested colleagues to screen participants before they were interviewed by me. Therefore, I called on nurses from the NICU to obtain a list of potential participants that met inclusion criteria. Once potential participants were identified the nurse contacted them and completed a return postcard giving me permission to contact them with more information about the study. I did not allow participants to be included in the study if the mother and child had been a primary patient of mine during their NICU stay to avoid the dual role neonatal nurse practitioner-researcher conflict (see Appendix B).

### *Recruiting/Gaining Access*

Concern for possible harm guided informal screening conversations with potential participants prior to the invitation to participate in research. Areas of concern included potential vulnerabilities of participants, participant's ability to understand and express the concept of multiple narrative meanings, and the researcher's perceived authority and influence with respect to participants. Researchers should not abuse their authority to encourage people to participate in research that might adversely affect them in some way.

When I suspected that a person would be harmed by what they disclosed, then I was obligated to raise that concern with the individual prior to obtaining their consent to participate. I remained aware that asking mothers to tell their stories could elicit repressed feelings of anger, sadness and other emotional responses due to sensitive subject matter. Therefore, each participant was made aware of that possibility prior to consenting to participate in the study and the

participants were provided with a list of references for support groups and counseling services in the participant's local area (see Appendix G). Participants were informed before entry into the study that they could discontinue the study at any time during the research as well as withdraw data once the interviews were completed. No subjects chose to discontinue their study at any stage of the research process.

### *Providing Participant Information and Debriefing*

Research participants were informed of the nature of the research from the onset of the study in order to establish and maintain trust between researcher and participant and so that participants could provide free and informed consent before entering the study. There was also a time for debriefing following the participant interviews, providing participants the opportunity to ask questions, so that if there were any misconceptions during the study, they could be clarified and any disagreements of alternative interpretations could be discussed and described. As part of the debriefing process, I wanted to ensure that the interview ended well. That was done by inviting the participant to say anything else she thought might be relevant to the topic or the interview process that was not previously mentioned. This allowed for new information to emerge.

### *Follow-up*

Following the interviews, participants were asked if they would mind being contacted afterwards for short (phone, email or face-to-face) follow-up in case material came up in the transcript which wasn't quite clear. Participants were also provided with my contact information should questions or concerns arise after the interview ended. I encouraged participants to send me any written comments or

make contact with me by phone or email if they thought of any points they would like to make after the interview ended. Then, I thanked participants and let them know that the time and energy that they committed to by agreeing to and undertaking multiple interviews was appreciated. I also explained that I would mail them a copy of the study or any publications that were derived from the study once completed. Finally, written thank you notes were mailed to each participant's residence following the third interview. Three participants (Raelee, Suzie and Elizabeth) were involved throughout the research process providing review of interview transcripts and offered clarifications and confirmation of my interpretation of story types and themes identified during the study. One participant (Abbey) chose not to participate in this process due to time constraints and numerous family crises unrelated to her baby.

### *Informed Consent*

I endorsed Munhall's (2007) concept of process consent, that consent to participate in research is not an all or nothing, one-time agreement but rather a mutually negotiated, ongoing process between researcher and participant. This approach to obtaining consent was mandated by the open-ended, unpredictable character of narrative inquiry and the depth of self-disclosure that participants communicated. Therefore, I obtained an initial consent form followed up by multiple additional signed authorizations to continue prior to each additional interview, and we had ongoing informal periodic conversations regarding consent throughout the process. Participants were encouraged to use referral services if they found the interview process disturbing and they were informed that they were free to withdraw from the study at anytime (Munhall, 2007). None of the

participants indicated to me that they sought counseling at any point during the study or immediately following the study.

The participants were also sensitized to the issue of multiple narrative meanings from the outset. This helped alleviate the common misunderstanding among narrative research participants that the researcher will ultimately convey the participant's own story just as the participant understands it. Specifically, the participants were made aware that their personal narrative will be re-narrated by the researcher in the course of analysis. Participants were told that this process would be collaborative. Mishler (1986a) comments, "If we wish to hear respondents' stories, then we must invite them into our work as collaborators, sharing control with them, so that together we try to understand what their stories are about" (p. 249). A brief statement to this effect was discussed with each participant and the issue periodically revisited during the process consent (see Appendix D and E)

#### *Ethical Approach to Interviewing*

Having addressed the issue of multiple narrative meaning during the consent process, this issue was set aside when the interviews began. When the first interview began, I clarified to the participant that the focus was now on their personal story of their NICU experience and I bracketed considerations about its subsequent interpretation or renarration. In other words, participants were encouraged to tell their story in their own words from their own perspective. Participants were informed when their remarks were being recorded. As the interview proceeded, I continually monitored the vulnerability and consent of the

participant, for the reasons outlined earlier. As researcher, I used intuition and judgment to avoid harm and maintain informed consent throughout the process.

#### *Privacy and Anonymity*

Participants were provided with anonymity by protecting the identity of participants. Participants were given the opportunity to choose a pseudonym or one was assigned to them. Every effort was made to protect individuals, as well as third parties who figured into their narratives, from undue exploitation in the process of telling their stories. Only the researcher had access to the data sets, and participant's names. Research data and participant identification was stored in locked files in a safe location designated by the researcher. Participants were informed that interview audio tapes would be maintained in a secure location by the researcher for a period of five years and then the tapes would be returned to the participants or destroyed.

#### *Protection from Harm*

Although qualitative researchers do not physically alter the participants with interventions, qualitative interviews do invade participants' space and psyches (Munhall, 2007). Such invasions are often therapeutic, however, they have the potential to pose possible risks and therefore the following precautions were taken to minimize harm to participants in this study. The possibility of triggering an emotional response within a participant was real and this possibility was taken seriously by the researcher. As an experienced nurse practitioner, I attempted to be supportive and manage the interview with good clinical judgment. If the participant showed signs of emotional distress during or following an interview or the participant felt as though she may require the services of a

professionally trained therapist or counselor to deal with particularly painful memories that had resurfaced, I was prepared to assist her in locating medical professionals within her community that specialized in that service. However, none of the study participants identified a need for such assistance throughout the research process.

Inaccurate portrayal of participants or situations may also cause harm. Participants were therefore encouraged to validate authentic representation during and after the analysis.

#### *Analyzing Data/Multiplicity of Meanings*

During the analytic phase, the multiplicity of narrative meaning became evident. Following the transcription of the interview, there were at least four separate phases of analysis. First, I consulted with participants to ensure their transcripts accurately reflected what they said. Second, I coded the transcripts according to my own intuitions and analytic methodologies. During this stage, I wrote in transcript margins and a journal about my personal reflections and feelings about the analytic process. I also maintained a reflective dialogue on a regular basis via email conversations with my Dissertation Chair, Dr. Karen Saucier Lundy regarding my thoughts and ideas related to the study. Specifically, I reflected on my own perspectives and interpretations as they might impact on the analysis and participant. Third, I reviewed the interpretations in conjunction with my personal reflections and addressed any ethical concerns that came to my attention with Dr. Lundy. For example, we discussed our desire to portray a balanced perspective of mothers' positive and negative experiences because

both provided insight into motives, expectations, aims, and convictions of the persons involved. Finally, I solicited participants' feedback on my interpretations.

The degree of participant participation was documented. Given the inherent multiplicity of narrative interpretation, I believed it was important to offer participants the opportunity to have their interpretation stand along with the researchers' interpretation, especially when there were significant discrepancies between the two. This was consistent with the belief that there is no one "truth" but rather a range of interpretations as we define our stories.

As stated earlier, three out of four participants chose to undertake this activity. Three participants reviewed their personal interview transcripts and determined that they accurately reflected what they had said in interviews. Three participants also provided feedback on my interpretations of their story types and common themes identified from the transcribed interviews. One participant declined to participate in this process due to the time constraints placed on her as a working mother and due to multiple family crises unrelated to her baby.

## Study Design

### *Research Setting*

This study aimed to elicit and analyze the stories that mothers told about their NICU experience. Study participants were recruited from a 55 bed, level III regional perinatal center in the Southeast that provides care for critically ill newborns, requiring staff trained to treat the smallest, sickest and most fragile babies. About 80 percent of the NICU admissions were because of premature birth.

The NICU can be an overwhelming place, filled with state-of-the-art medical equipment. It is organized into two separate units, the level III NICU for the more critical infants recovering from congenital diseases, illness, or from premature birth and the level II NICU for more stable infants who are learning to eat and grow and preparing for discharge home.

### *Sample Selection*

This study used a qualitative purposeful sampling design strategy as defined by Patton (2002) to recruit participants. Participants were selected because they were “information rich” and illuminative, that is, they offered useful manifestations of the phenomenon of interest. Sampling then, was aimed at insight about the phenomenon, not empirical generalizability from a sample to a population (p. 563). While one cannot generalize from relatively small samples, even single cases selected purposefully, offers information that one can learn from—and learn a great deal from them—often opening up new territory for further research (Patton, 2002, p. 230).

Purposeful sampling is typically not about sampling people per se, but rather events, incidents, and experiences (Sandelowski, 1999). Therefore, in this study, mother’s oral stories, as told in in-depth narrative interviews, were the primary sources of information. Participants were also given an opportunity to share with the researcher artifacts (journals, letters, poetry, diaries, photographs, memorabilia, art) collected from their NICU experiences for the stories embedded in them.

Mothers as participants were invited to enter into the study by virtue of their intimate knowledge of and ability to communicate the experiences of having



had an infant requiring care in the NICU. This study provides a retrospective look at the NICU experience. Therefore, mothers and their infant's must have been discharged from the NICU prior to being invited into the study.

#### *Inclusion Criteria*

Primigravidas (First pregnancy)

Prematurity (gestational age of 24 weeks to 39 weeks)

Time in the NICU (minimum of 1 week)

Discharge from the NICU at least 6 weeks but no longer than 6 months

Infant must be living at the time of the interview

#### *Exclusion Criteria*

Multigravida (Second or subsequent pregnancy)

Term/Post-term infants (gestational age 40-42 weeks)

Mothers of multiples

Mothers of infants with genetic disorders

Discharge from NICU > 6 months

Time in the NICU < 1 week

Mothers of infants that died during or following the NICU course

#### *Sample Size*

In narrative research the sample need not be large as it is based on information-rich cases, and the inclusion criteria are fairly narrow. The sample was narrowed to create a homogenous sample by using inclusion and exclusion criteria listed previously. Selectivity of participants helped to keep the findings in context. Future studies can then focus on other specific groups of mothers excluded from this study.

For the purposes of IRB approval, the sample size was projected to be a minimum of four participants, based on expected reasonable coverage of the phenomenon and purposes of the study. The decision reflected the need to achieve a balance between the time available to work on the study, and the longitudinal nature of the study in which the four participants were interviewed three times each for a total of 12 separate interviews lasting one to three hours. The decision also reflected the depth and associated time needed to undertake the analysis.

The study allowed for sampling to be an ongoing process where the researcher is given the opportunity to add participants as needed when new ideas and concepts emerge and can be followed up. However, the narrative approach to sampling does not demand that the sample be saturated. The purpose of the study was to capture the lived experiences of particular participants in order to understand their meaning perspectives, case by case (Riessman, 2001; Janesick, 2003; Chase 2005). The design was both flexible and emergent in structure.

#### *Participant Recruitment Strategies*

The researcher gained access to the sample through the mediation of *gatekeepers*. The gatekeepers were nurses who identified an individual as a possible participant for inclusion in the study. Potential participants were then asked to complete a return postcard giving the researcher permission to contact them. I relied on gatekeepers in the site to advise me when to contact women who had given their permission for me to call them.

For potential participants who expressed interest and gave permission for the gatekeeper to do so, the gatekeeper telephoned or gave me a copy of the return postcard, with the participants contact information. I then telephoned each potential participant, described the study, and answered questions. The potential participant then made the decision to participate in the study or not. When a potential participant decided to participate she was then given a packet of study materials including a project information sheet, a sample consent form, and a demographic data sheet. All the participants who chose to participate in the study were given the study materials prior to the first interview. Ethics demand that the sample consist of voluntary and willing participants who are not coerced in any way (see Appendix C, D, E, G, & M).

#### *Timing of Interviews*

In narrative inquiry, it is important that some time has elapsed since the actual event. In this study, participants had to be discharged from the NICU for a minimum of six weeks and no longer than six months to be included in the study. Hurwitz (2004) noted that "time, itself, is required to distance the subject of experience from actuality, to allow sensory, emotional and intellectual interpretation to take place; to allow views to form about what has happened or is happening in the context of wider frames of reference, be these factual, biographical, temporal, or mythic" (p. 424).

Past, present and future time is a central concern in narrative study as opposed to "lived time" in phenomenological studies (Sandelowski, 1999, p. 80). Hurwitz (2004) further explained that "recounting involves shaping and ordering events in ways that go beyond questions of sequence and chronology, to include

valuation of significance, ascriptions of causation and above all of meaning" (p. 424).

The trajectory for this study encompassed events in a mother's narrative response to, history of, or lived experience with, having an infant who required care in the NICU. For the participants in this study, the trajectory included the experience of birth, admission to NICU, stay in the NICU, discharge from the NICU; current situation post discharge and present life situation; and future concerns. Although the NICU experience was the intended focus of inquiry in the beginning, for mothers the NICU experience included time leading up to entry into the NICU and extended beyond the NICU. This expanded view of the NICU experience was articulated in and through participant narratives and artifacts. These data sources played a key role in understanding how the NICU experience shaped and affected the participant mothers life. Since this trajectory served to organize participant's stories, information-rich cases representing this time period were sought.

### Data Collection Strategies

#### *Narrative Interviews*

The narrative interview was the tool through which the researcher gained access to the stories of participants. Narrative interviewing was well planned and prepared, although it did not follow a rigid structure or focus on single issues. The narrative interview did not follow the standard back and forth question and answer session of traditional interviews, instead the narrative interview was restricted to a small number of questions from the researcher and centered on

the flow of talk from the participants. The goal of narrative interviews is to limit interruptions so that the thread of the story is not lost.

The stories are grounded in the participants' own life worlds or experiences. The way they see the "truth" of their experiences is enclosed in the stories. Kvale (1996) noted that the narrative interview is most productive when the interviewer suppresses his or her own desire to speak and helps participants to produce spontaneous talk. Kvale (1996) described this type of interview as a journey in which the interviewer and the interviewee partners travel together, and where the latter tells the researcher of their 'lived world'. Participants who chose to participate were given the opportunity to choose the interview location. These locations included the participant's home, the researcher's home office, a conference room located at the hospital near the NICU and a coffee shop owned by one of the participants.

The goal of interpretive inquiry is to discover meaning and achieve understanding, a longitudinal approach with multiple interviews was preferred in that they are more likely to elicit private accounts from participants and give the researcher the opportunity to carefully review the audio taped interview prior to the next interview. This approach allowed the researcher and participant a second chance to make sure that understanding had occurred by revisiting issues and discussing new areas that had emerged from interview data collected in previous interviews. Reading the prior interview allowed the researcher to clarify initial interpretations and thus to ask crucial descriptive questions overlooked before. Clarifying questions and probes were then used to follow up on topics from the prior interview.

Benner (1994) noted that description is not as easy or straightforward as it may seem. She encouraged novice researchers to seek critique and review from experienced researchers, clinicians as well as study participants. Therefore, in this study, I sought critique and review not only from study participants but also from experienced researchers serving on my dissertation committee as well as neonatal nurse practitioner colleagues. I also invited review and critique from my experienced transcriber (Rebekah Young). Rebekah is part of the general community as well as the research community (she is an experienced transcriptionist with a master's degree in public health and she is a public health educator). Rebekah simply stated that my interpretations were reasonably documented and were logically coherent (based on her listening to audio tapes, her verbatim transcription and her reading of my interpretations of narrative excerpts from interview transcripts).

Poland (2001) noted that researchers should not overlook the opportunity to involve transcribers in the study beyond their function as recorders. After all, other than interviewers and/or study investigators, transcribers are the only people to be exposed to the interview in its entirety. In the Brantford study, the transcriber was encouraged to provide feedback (typically in writing at the end of the interview) about her reactions to the interviews--not only its content, but also her perceptions of the nature and quality of interactions between interviewer and interviewee (the time she took to provide her reactions was included as paid time). The quality of the transcriber's contributions was variable, but it was frequently found to be useful for researchers. This was particularly helpful when

the transcribers assessment and those of the researcher were at odds, forcing the researcher to reexamine assumptions and conclusions about the interview.

All of these people (dissertation committee, transcriber and colleagues) helped me to uncover blind spots and systematically avoided questions. Interpretive dialogue began with the first interview so that data collection, inquiry, and analysis were not separated. The critique and review that I received allowed me, as a novice researcher, to pursue lines of questioning that were not generated by the study itself, ensuring dialogue throughout the process (Benner, 1994).

#### *Technique for Eliciting Narratives in Interviews*

The purpose of eliciting narratives in the current study was to obtain qualitative descriptions of the NICU mother's life worlds with respect to interpretation of their meaning and to better understand the moral concerns embedded in their stories. The interview approach taken here was a semi-structured in-depth interview. The researcher used narrative interview techniques described by Clandinin and Connelly (2000), Kvale (1996), Mishler (1986) and Wengraf (2001).

The interviews were conducted in a minimally structured manner, influenced by Wengraf's (2001) biographic-narrative-interpretive method (BNIM), inviting participants to tell about their NICU experiences. Participants were encouraged to tell their stories with minimal interruptions from the researcher, largely confining the researcher to asking for participants to elaborate on or clarify information. This kind of "narrative" interviewing created an environment

where participants could structure their own stories and bring up topics in the order most salient to them (See Appendix N & O).

The BNIM is a narrative interview design composed of three-subsessions. The first session began with a single initial question aimed at inducing narrative, and a particular focus of such a question—part or all of the individual's life story, their biography (in this case, the aim was to obtain the participant's narrative of her NICU experience). Interventions by the interviewer were limited allowing the participant to take the floor, telling her story with minimal interruption by the interviewer. For instance, in my first subsession with participants, I communicated the following:

I would like for you to tell me the story of your NICU experience, all the events and experiences that were important to you up until now. Start wherever you like. Please take the time that you need. I'll listen first, I won't interrupt, I may take some notes so that I can ask additional questions after you have finished telling me about your experiences. I will let you know you if the time that we arranged for the interview is running out.

This initial narration continues until the participant indicates clearly that they have no more to say; then there will be at least a 15 minute break for the interviewer to review notes and prepare questions.

Subsession two was scheduled at the participants convenience as near to the initial interview as possible. Preferably, subsession two took place within two weeks of the initial interview. During subsession two, the interviewer asked for more stories about the topics that were raised in the initial narration, following the



strict order in which they were raised by the participant and using the words of the participant in respect to topics. Even so, topics from session one may be missed or brought up out of order by the participant. The reason remains the same: The gestalt of the individual being interviewed must not be destroyed by the intervention of the interviewer. The questions in this phase were strictly for more story; designed to elicit more narrating about the topics initially raised, in the order they were raised by the participant. For example, the second subsession included the following questions to return the participant to narrative

Tell me more about topic X. Please describe the incident/experience of topic X in terms of time, place, situation, and participants. In the incident that you spoke about, what was the sequence of events? What happened first? What happened next? Then what happened? What finally happened? What significance did the experience have at the time it was occurring? What did it mean to you at the time? What significance does the experience have in your life now? Can you give an example of topic X? Are there any other things you remember happening? Do you remember or recall anything else? Can you give me ANY example of an occasion when...? Can you give me any MORE examples of similar events, incidents at that time/ of that type? Was there some particular CRUCIAL incident or situation or time that you can recall?

Immediately following the first two subsessions, I then took private time to complete self-debriefing or field notes. I used free association, trying to avoid the tendency to order, organize, or censor anything. For a 30-60 minute period, I wrote notes in a journal about thoughts that came to mind about the interview.

Thoughts were then sorted later. The rationale for this debriefing process was that debriefing notes, field notes or session notes were my record of the interview experience and what memories, ideas, and thoughts, it stimulated in me as the researcher. Debriefing notes were vital for the researcher's subsequent analysis of a particular interview (as well as being of great importance for the professional development of the researcher). These notes, according to Wengraf (2001), include material from the researcher's short-term memory that could be lost as the researcher talks to people, leaves the interview location, and does other things that distract attention away from the interview. According to Wengraf (2001) there is only one opportunity to get the maximum benefit and the data from the interviewer's brain: immediately after the interview before the interviewer moves on to other activities, or begins to think about other things (Wengraf, 2001).

The last subsession—subsession three—was always a separate interview. To prepare for it I completed a preliminary analysis of the material gathered in subsessions one and two. On the basis of that preliminary analysis and in light of the research purposes and theory questions, I developed a set of questions which included—but were not restricted to— the type of narrative-pointed questions used in subsession one and two. Subsession three was completely structured by questions arising from preliminary analysis of the material from the first two subsessions and the interviewer's concerns which provided a strong directional flow to the interview. Here any question was asked about topics not previously mentioned.

Interview data and were then transcribed verbatim. Debriefing notes and/or field notes in this case were recorded on paper, not on audio tape. Analysis was directed toward understanding each participant's experiences as perceived by that individual over time as a case, each case was then compared within and between other cases.

#### *Artifacts from the NICU*

Bal (2007), defined *narratology* as "the theory of narratives, narrative texts, images, spectacles, events; cultural artifacts that 'tell a story' " (p. 3). Bal, described "*narrative text* as a text in which the agent relates ('tells') a story in a particular medium, such as language, imagery, sound, buildings, or a combination thereof" (p. 5). Bal uses text concepts and artifact interchangeably (p. 6).

Artifacts, in this study were a rich source of texts and aided in understanding life in the NICU from a mother's perspective. These data sources allowed access to the differentiated particular, helping me as the researcher and reader to understand the complexities of the participants past experience. By combining the participants' verbal stories with stories represented in other data sources, i.e. artifacts, a relation of staggered and overlapping narratives was created. This perspective allowed for a multifaceted, complex view of past experience (Fleming, Riegle & Fryer, 2007, pp. 82-83).

Non-discursive, aesthetic forms of expression such as artifacts, journals, photography, art, poetry and memorabilia assisted mothers to find meaning from their NICU experience and may have helped them to cope with diversity of experience (Baldwin, 2005, p. 1026; Clandinin & Connelly, 2000; Radley, 1999).

Artistic expression also provided the participant mothers' with an additional means of telling their story. However, it did require that I remained sensitive to the narrative features of such media.

The language of arts in narrative inquiry has been described by Mello (2007). She suggests that art can be used at the beginning of research to encourage storytelling and reflection or it can be used as a tool to make sense of the stories told as well as to construct a research text (Mello, 2007).

Photographs, for instance, often provide a visual narrative and can be used as tools to begin storytelling and its meaning-making process. Poetry may also be collected, as it may offer a space for sharing experiences and reflections. Short stories may also be included as they may provide an analogy to reflect on personal difficulties. The novel may also be an artistic tool by allowing inward and outward reflective movement. Letters and journal entries informed the current narrative inquiry by emphasizing the dialogic relationships that exists between mother and child or mother and nurse. Journal entries and letters illuminated themes that individuals considered important.

In this study, it was noted that narratives were slightly altered in different media to protect the identities of participants' but included actual observations, diagnoses, interventions, and interpretations made by physicians or healthcare professionals about the infant in the NICU. For example, one of the participant mothers in this study maintained three separate journals, each with different purposes. She had one journal that she would write in while in the NICU about her true feelings and reactions to her experiences. Even though she did not share the information contained in that journal with me, she indicated that there

were thoughts in that journal that were just too painful to share with others but she found it helpful to write them down.

She had a second journal that she kept for her baby. In that journal, the focus was the baby's life story. She outlined the daily happenings in the NICU. She kept track of the baby's weight, progress, and setbacks. She wrote letters and notes of encouragement to her baby. She told him about all the people that loved and cared for him while he was in the NICU.

In a third online public journal site, she posted progress reports for other family members and friends who wanted to keep track of the baby's progress but who did not have access to the NICU. The participant noted that in this online public journal, she tried to remain positive. She did not want others to be worried about her, but wanted their attention to be focused on the baby. She also wanted to protect her loved ones from the emotional rollercoaster of the NICU that she was experiencing.

In addition to journal entries, this participant mother posted a photographic diary documenting her baby's journey through the NICU. Friends and family then had the opportunity to respond by posting words of encouragement and prayer to both mother and baby on the website.

According to Mello (2007), the arts can inform a study by using creative research texts presentation as part of the analysis, during the transition from field texts to research texts, and as a way of informing the meaning made, and be considered as art-informed narrative inquiry (Mello, 2007, p. 214). Narrative inquiry can also be considered arts-based and arts-informed simultaneously. Mello (2007), noted that there is no need to follow an either/or path. Using art in

narrative inquiry has to do with empowering researchers and participants, inviting readers to make their own conclusions, supporting construction of personal knowledge, and honoring multiple perspectives.

Following interviews with the participants, time was reserved for participants to share and explain artifacts such as photographs, video's, poetry, art, journals, memorabilia, etc. collected from their NICU experience. Multiple data sources and contexts were preferred in order to create a more naturalistic account and to prevent an overly narrow perspective of the situation (Benner, 1994, p. 118), Hearing only a single story or synthesis may make reconstruction difficult. Understanding was aided through access to multiple experiences and personal stories told by participant mothers' over time (Fleming, Riegle, & Fryer, 2007, pp. 82-83). These data sources were also included in the analysis and results.

### *Reflexivity*

The interview process that took place in this study was reflexive in the sense that it engaged participants in a collaborative process. The researcher in this situation treated the participant as expert, with the task being to effect change in the researcher's understanding of the phenomenon of interest. Above all, this interpersonal relationship required that the researcher be a good container, in other words, that I listened empathetically but without judgment, feeling from within the participant's emotional space. In so doing, the task of the researcher in the data-gathering phase was to explore and clarify the *personal* meanings of the participant's experience based on new insights (Denzin & Lincoln, 2003; Josselson, 2007).

However, the task in the report phase was to present conceptual implications of these meanings to both the academic and healthcare community. Thus, at the level of the report, the researcher and the participant had different end goals. That meant that there was a division between the personal story told by the participant and the narrative that exemplified something of theoretical interest created by the researcher (Josselson, 2007).

Insights from Josselson (2007) were followed to approach the participants in the most ethical way. I explained at the close of the interview that what was written about the interview would depend on the general conclusions that were made of the entire group. What was written about a particular individual may not feel to them as though it was fully about them. Certain themes were highlighted to make a point and names and places were disguised so that individuals were not recognized in order to protect their anonymity (Josselson, 2007).

#### *Ending the Interview*

Ethical considerations were as important at the end of the interview as at the beginning. This was particularly true, when participants had just exposed important aspects of their lives and may have felt a close connection to the researcher. Therefore, it was important for both researcher and participant to voice how they felt about the experience and to note the meaningfulness of the relationship and the knowledge generated from the research process. As the interview ended, I invited participants to reflect on the experience as a way of bringing the process to a close by asking "How was this experience for you?". Regrettably, this discussion was not audio taped. In future studies, I would recommend including this time of reflection while the audio tape is running.

I also remained alert to signs of hesitation or discomfort on the side of the participant and was ready to empathetically process or clarify any ways the participant may have felt distressed by the interview ("That must have been very difficult for you;" or "How painful that must have been for you."). I also invited the participant to ask whatever questions she had for me ("What questions do you have for me as we end our time together?").

As the interview relationship came to a close, I gently and clearly reemphasized my role. For example, "As you recall, when we began this research process together, I explained that my role was that of a researcher-investigator and that of a nursing scholar reporting to the academic and clinical nursing community about what I had learned. If you are having feelings of distress following our interviews, or if our interviews caused painful memories to resurface and you feel that you are in need of a professionally trained therapist or counselor, I will be happy to assist you in finding resources available to you in your local community." Participants were then provided with my contact information and referred back to the handouts that were included in their research materials.

### Analysis of Findings

I conducted three interviews with each of the four participants for a total of 12 interviews lasting one to three hours in length. Each interview was audio taped and later transcribed verbatim by an experienced transcriptionist. I also, listened to the original audio taped interviews and compared the audio-recording with the written transcription of the interviews on multiple occasions. The purpose



of this study was to better understand the stories told by mothers who had the experience of having an infant the NICU.

In order to identify sections of the transcription for closer examination, I looked for a working definition of "narrative" that would help me to separate the narratives from other forms of discourse that might appear in the transcriptions, such as arguments and question and answer exchanges (Riessman & Quinney, 2005). As noted previously, for some purposes, "narrative" is an inclusion category and "story" is restricted to texts that have characters, events, complications, and consequences (Coffey & Atkinson, 1996). Alternatively, narratives are considered as synonymous with stories, as oral or written versions of personal experience that people use in social situations to convince the listener that something actually happened (Riessman, 1997). Riessman (2003) made a further distinction by using the term "personal narratives" to describe discrete stories restricted to answers to single questions. In the present study, I did not make these distinctions and considered the terms synonymous. I frequently interchanged the terms narrative, story and personal narrative.

Sometimes the decision was clear about which segments of the interviews represented narratives. The participant signaled when a story began and when it ended by using entrance and exit talk. In some instances, a particular story was triggered by something that proceeded it or something in conversation that reminded the participant of a story, which did not seem to relate topically with the talk in progress. Frequently, when completing the story, the participant searched for a response or confirmation from me. Other narrative segments were not so

clearly bounded and I selected segments based on my theoretical interests (Riessman, 2003).

No standard method was applied in analyzing the identified narratives; rather, a variety of approaches drawn from the works of several authors (Charon, 2006; Clandinin, 2007; Frank, 1995; Kvale, 1996; Lieblich, 1998; Poirier & Ayers, 1997; Riessman, 1993) contributed to the study. The goal was to bring out the meaning of the stories told by mothers in semi-structured in-depth interviews and in the artifacts collected from their NICU experience. The primary task with the variety of approaches was to decipher meanings and moral concerns inherent in the data and render them in a form consistent with the research questions. How this process transpired represents the art of this kind of work. Whether doing thematic analysis, or reading data for holistic content (shared story types), or a combination of these approaches, collaborative and participatory research approaches helped the researcher investigate the data using multiple analytic methods.

In using all methods, narrative analysis required multiple readings. I invited other readers (dissertation committee members, transcriptionist and clinical colleagues) to review the empirical data to open up multiple perspectives and provide additional viewpoints and interpretations. The researcher also sought to create an environment in which collaborators felt that their perspective was genuinely valued and respected. Research participants were also given opportunities to clarify, react, and respond to the researchers' interpretations (Josselson & Lieblich, 2003; Patton, 2002).

In the following section, I examine several approaches to working with personal narratives that were identified in the literature and selected strategies to identify and manage the narrative data that seemed effective when I applied them to my study. My overall approach was holistic so I first examined each participant's story in its entirety. When I looked at sections of the participants' narrative text, I considered them in the context of the other parts of the narrative.

### Holistic-Centered Content Perspective

Analysis of interview transcripts obtained in the current study began by following Lieblich (1998) proposed process for reading narratives for content in a holistic manner:

1. Read the material several times until a pattern emerges, the significance depends on the entire story and its content.
2. Write down the initial and global impression noting exceptions to the *general impression as well as unusual features including contradictions and unfinished descriptions, episodes that seem disturbing to the teller, episodes that produce disharmony in the story.*
3. Decide on the foci of content or themes to follow from beginning to end, foci are often distinguished by their repetitive nature and the number of details the teller provides about it, however omissions of some aspects in the story, or a very brief reference to a subject can sometimes also be interpreted as indicating the focal significance of the topic.
4. Using colored markers (following the method applied by Brown, 1988), mark the various narrative features and transcendent themes in the story, reading separately and repeatedly for each one.
5. Keep track of results in several ways: follow each theme throughout the story and note the conclusions. Become aware of where a theme appears for the first and last times, the transitions between themes, the context for each one, and their relative salience in the text. Be aware of episodes that seem to contradict the theme in terms of content, mood, or evaluation of the teller (pp. 62-63).

## Structural and Functional Analysis

Next, interview transcripts were read for their structure and function.

Riessman (1993) preferred this approach because it avoided the researcher's tendency to read a narrative simply for content, and the equally dangerous tendency to read it as evidence of prior theory. She recommended beginning with the structure of narrative, asking the following questions: How is it organized? Why does an informant develop her tale *this way* in conversation with *this* listener?

Riessman (1993) suggested starting from the inside, from the meanings encoded in the form of the talk, and expanding outward, identifying for example, underlying propositions that make the talk sensible, including what is taken for granted by speaker and listener. This strategy privileges the teller's experience, but interpretation cannot be avoided (p. 61).

Individual narratives, according to Riessman (1993) are situated in particular interactions but also in social, cultural, and institutional discourses, which must be brought to bear to interpret them. She noted that investigators should not bypass difficult issues of power: Whose voice is represented in the final product? How open is the text to other readings? How is the researcher situated in the personal narratives that were collected and analyzed? It is essential, in Riessman's view, to open up these interpretive issues for readers to see.

There are a wide variety of definitions of what constitutes a narrative and an equally wide variety of approaches to the structural and functional analysis of

narratives. I followed the guidelines outlined in three traditional approaches (Labov, 1972, 1997; Gee, 2005; Riessman, 1993, 2008) to review transcripts.

Storytelling typically involved an extended account, which was longer than exchanges in most interactive conversation. When I first met with each participant, I made the following statement to encourage storytelling:

I would like for you to tell me the story of your NICU experience, all the events and experiences that were important to you up until now. Start wherever you like. Please take the time that you need. I'll listen first, I won't interrupt, I may take some notes so that I can ask additional questions after you have finished telling me about your experiences. I will let you know you if the time that we arranged for the interview is running out.

Although the participants responded to the statement that I posed, they often offered sections of talk that were fragmented and showed a degree of decontextualization. If I had reduced these narratives to fragments that were out of context, I might have missed crucial interpretive understandings (Riessman, 1997). Therefore, I tried to retain the context as I reviewed the transcribed versions of the interviews and listened to the original audio recording several times before selecting large portions for further examination. These transcriptions included subtle features of discourse, such as breath intakes, non-lexical sounds (uh-huh), verbal emphasis (words in capitals), pauses, and word repetitions (Riessman, 1993). I identified the narrative segments that I planned to examine in more detail by looking for two types of narrative structure: core narratives and poetic structures. When I identified a segment from the interview data that

appeared to be one of these two narrative structures, I bracketed it for re-transcription.

### *Core Narratives*

The first step taken in the structural and functional analysis was to consider the stories that followed the temporal ordering of the action; that is, there was a sequence based on linear time and shaped around characters, setting, and plots. Here, I located certain narratives that had structural features such as abstract, orientation, complicating action, evaluation, and resolution and coda (Labov, 1982; Labov & Waletzky, 1997) and reduced the transcriptions to core narratives (Riessman, 1993).

### *Poetic Structures*

The second step taken in the structural and functional analysis was to look at narratives using Riessman's (1993) technique (adapted from Gee) of creating poetic structures to find meaning. Gee (2005) described another way to analyze interview text structurally. He noted that each line of a transcript represents a tone unit, that is, a set of words said with one uniform intonational contour that is, said as if they "go together" (p. 107). He then organized the text into "stanzas," a language unit that he described as "clumps" of tone units that deal with a unitary topic, event, image, perspective, or theme, and which appear to have been placed together (p. 128).

Each stanza is a group of lines about one important event, happening or state of affairs, at one time and place, or it is focused on a specific character, theme, image, topic, or perspective. When time, place, character, event, or perspective changes, we get a new stanza. Gee (2005) uses the term "stanza"

because these units are somewhat like stanzas in poetry. According to Gee (2005) stanzas represent a piece of the larger organization of a story (p. 128). For example, the setting of a mother's story is just one piece of the larger narrative. Finally, I identified the narrative themes that I thought represented and encapsulated important narrative features.

#### Five Narrative Features and Transcendent Themes

In chapter one, I briefly mentioned the five narrative features—temporality, singularity, causality/contingency, intersubjectivity, and ethicality that Charon (2006) called the “bedrock aspects of narrative practice” (p. 39). In this section, I elaborate on each to describe how I examined the narratives in this study for these features as the final step in the analysis.

##### *Causality/Contingency*

By definition, a narrative has a plot or emplotment, that is, it is organized by a series of separate events or states of affairs that come together with a meaningful causal relationship tying the events together. The storyteller offers interconnectedness and intention by their creative placement of the narrative elements—incidents, episodes, and actions. Chambers and Montgomery (2002) described the emplotment in bioethics as follows, “Plot is meaning. Plot shapes a story to represent the significance of its events and to reveal their meaning for the teller and (the teller hopes) the listeners.” (p. 81).

Depending on the storyteller's point of view, intention, and stance, the same set of events can be “told into” different plots. New events may be discovered or discerned, and old ones may be given a new causal or temporal construction.

The NICU is full of events that are random, unpredictable, unexplainable, and unknowable. Emplotment may help the mother to address her experiences with the unknown, to conquer her fears, to brave predicaments in which she finds herself. The future that she had imagined for herself and her child may be suddenly changed by the NICU experience. Suddenly her future is unknown, but as this mother waits, she may form stories in an attempt to make sense of the unknowable, to create order from the chaos and to create a new outlook for the future.

Narrative emplotment celebrates uniqueness and respects the unity of events while representing it. As Charon and Montello (2002) suggests, "it is only when human representations frame events or states of affairs that beginnings, middles, and ends are mapped and measured and that meanings emerge from them" (p. 50).

Charon noted that clinical practice is consumed with emplotment. Diagnosis itself is the effort to impose a plot onto seemingly disconnected events or states of affairs. She explains that healthcare practitioners test one diagnostic algorithm after another—and the more seasoned we get, the more automatically and unconsciously this process occurs—in the effort to categorize this set of events, in the effort to emplot it (p. 50). The plots created in the NICU are very often about endings. "They point to human ends, both patients and their practitioners use emplotments to understand or imagine the vectors of life, the plottedness of life, the inevitability of death, and the narrative connections among us all" (p. 51). Reading narrative for causality/contingency may help answer the following questions: What does the story reveal about the mothers' search for



meaning? How are events arranged? How is the beginning, middle and ending arranged?

### *Temporality*

In his comprehensive *Time and Narrative*, philosopher Ricoeur (1984) asserts that there is a correlation between the activity of narrating a story and the temporal character of human experience. Putting it another way, Ricoeur suggests that, "time becomes human to the extent that it is articulated through a narrative mode, and narrative attains its full meaning when it becomes a condition of temporal existence" (p. 52).

Narratives, as Charon (2006) suggests, "teach us where we come from and where we are going, allowing us to understand the meanings of our own lives... We attempt to understand time as it passes, time as it stamps us, time as we waste it and use it and live through and beyond it, and it is through narrative thought that humans are able to come to at least provisional accord with the relentless and merciful passage of time" (p. 42). In this sense, "temporality is subjective time as opposed to clock time or objective time... Lived time is the time that appears to speed up when we enjoy ourselves, or slow down when we feel bored or anxious" (Van Manen, 1990, p. 104).

The following questions about time may help the researcher to better understand time as experienced by mothers in the NICU: How do mothers' experience time? What is the temporal scaffolding of mothers' narratives? What is the verb tense? What does an hour, a day, a week, a month in the NICU feel like?

### *Singularity*

According to Charon (2006), "what distinguishes narrative knowledge from universal or scientific knowledge is its ability to capture the singular, irreplicable, or incommensurable" (p. 45). Nursing's impulse to be scientific leading toward replicability and universality has muted our realization of the singularity and creativity of our acts of observation and description.

When mothers in the NICU complain that they are treated like numbers or items, they are voicing their concerns about their singularity being undervalued. It is through narratives that patients can attempt to take back their singularity, their subjectivity. Understanding a mother's personal situation is most essential to the nurse knowing and understanding the meaning of health in terms of individual well-being. If nursing care is to be more than habitual or mechanical, the capacity to perceive and interpret the subjective experiences of others and to imaginatively project the effects of nursing actions on their lives becomes necessary (Carper, 1978, p. 22). When reading a text for singularity, one can answer the following questions: What are the individual stories told by mothers? How is the mother's story unique?

### *Intersubjectivity*

Charon (2006) described "Intersubjectivity as the situation that occurs when two subjects, or two authentic selves meet" (p. 51). We exist within a web of relationships. "This relationship has cognitive, perceptual and ontological aspects" (51). "It follows that narrative acts build relationships as they convey information, emotion, and mood" (p. 52).

“Writing, or telling, gives a speaker the authority and the opportunity to reveal the self. Reading, or listening, requires an equally perilous and daring ability to acknowledge another self, to open oneself to being penetrated by another” (Charon, 2006, p. 53). The relation is one of reciprocity.

Watson (2003) noted that

the task of nursing and health and healing is related to the very nature of our shared humanity...When working with others during times of despair, vulnerability, and unknowns, we are challenged to learn again, to reexamine our own meaning of life and death. As we do so, we engage in a more authentic process to cultivate and sustain caring, healing practices for self and others. Such care and practices elicit and call upon profound wisdom and understanding, beyond knowledge, that touch and draw upon the human heart and soul. (pp. 197-198)

Charon (2006) insists that “our intimacy with patients is based predominantly on *listening to what they tell us*, and our trustworthiness toward them is demonstrated in the seriousness and duty with which we listen to what they entrust to us” (p. 53). The relationship between healthcare providers and their patients is based on a complex text that encompasses words, silences, physical findings, pictures, measurements of substances in the body and appearances. Therefore, Charon added, our “transformative intersubjective connections among relative strangers can be fused and nourished by words” (p. 54).

Charon (2006) noted that it is important for healthcare practitioners to recognize that our responsibility toward our patients requires being a “dutiful and

skillful reader” of patients in our care (p. 54). The intersubjective meetings that occur in the NICU between relative strangers, are replete with the occasions of great personal discoveries. These meetings according to Charon, “are therapeutic to the extent that they enable one person to tell while the other person listens, and to tell and therefore to know of ‘what’s meaningful to her right now” (p. 55).

Reading a narrative for intersubjectivity can help the narrative researcher answer the following questions: How did we get here together? What are the desired expectations? What is the basis of trust? How might mothers’ stories promote dialogue among healthcare providers in order to preserve and extend responsiveness, care, comfort, safety, hope, and opportunity for mothers’ and their ill infants in the NICU and beyond?

### *Ethicality*

Newton (1995) suggests that “a narrative is ethics in the sense of the mediating and authorial role each takes up toward another’s story... storytelling lays claims upon all its participants, those circumscribed within the narrative as well as those...witnesses and ethical co-creators from without—its readers” (p. 48). According to Charon (2006), “the receiver of another’s narrative owes something to the teller by virtue, now of knowing it” (p. 55). This is according to Charon “the intersubjective bridge to narrative’s ethics” (p. 55).

Charon explained that “beyond the intersubjective bridge of narrative ethics, we enter the ethical dimensions of stories” (p. 55). “Stories allow us to confront valuable aspects of human moral experience by representing particular events, characters, obligations, rights, and wrongs in language, stories display

for readers varieties of ways in which to consider what one "ought" to do or how one might judge the actions of others. The problem lies in knowing how to judge things and this is a problem that narrative's ethical visions help us answer" (p. 56).

Vitz (1990) noted that "one may view narratives as the laboratory of moral life...moral life is far more than abstract dilemmas and propositions. It is narratives that provide an almost endless detailed and lifelike description of the moral dilemmas people actually experience" (p. 718).

Reading stories for ethicality may help to answer the following questions: What does the story deem to be the right way to live? What does the writer or the teller deem to be the right way to live? What are the issues in the story that depict moral concerns? What aspects of the story represent concerns about public and private life, justice, goodness, friendship, fidelity, love? How should one act in such a world? What are the differences between the author's moral vision and the reader's own moral vision? How might mothers' stories help shape the practice of nurses and healthcare providers in ways that are respectful of the possibilities that their stories disclose?

Charon (2006) insists that

Narrative ethics exposes the fundamentally moral undertaking of selecting words to represent what before the words were chosen was formless and therefore invisible and unhearable. It is the very act of fitting language to the thoughts and perceptions and sensations within the teller so as to let another 'in on it' (that other, the listener or the reader, now bound intersubjectively if, indeed, authentic contact is made) that

constitutes the moral act. The telling exposes the moral freight of the story (along with, of course, its aesthetic freight, its psychological freight, its freight of delight) not only to the light of day but also to the lights of others. (p. 56)

Charon (2006) asserts that, the combination of the need to know with the duties incurred by virtue of knowing defines an *ethical relation*. In other words, the listener/reader does not remain untouched through the act of listening/reading but rather becomes open to fundamental transformation by virtue of having listened/read (p. 56).

Charon (2006), insists that “the five features of narrative are not isolated one from the other. Instead they arise in congress, intertwining, emboldening one another as the reader and writer try in unison to find meaning in the words. Like any organic whole, the narrative is made up of its conceptually separable ‘organ systems,’ but in its living whole, the narrative combines these elements, and life is breathed into static words and forms” (p. 59).

#### Returning to the Hermeneutic Spiral

To put my data analysis process into perspective, I will once again return to Kvale (1996) who noted that interpretation of meaning is characterized by a *hermeneutical circle or spiral*. The understanding of an interview text or in this case an artifact collected during a mother’s NICU experience takes place through a process in which the meaning of separate parts of the story are determined by the global meaning of the whole story.

Analysis in this sense, takes on a back and forth process between the parts and the whole. This may mean that in the beginning there is a vague and

intuitive understanding of the data as a whole, its different parts are interpreted, and out of these interpretations the parts are again related to the whole. In this hermeneutic tradition of understanding, Kvale (1996) noted that circularity is not viewed as a “vicious circle,” but rather implies possibility of a continuously deepened understanding of meaning (p. 48).

By utilizing the techniques described in this chapter, my goal was to read an interview through first to get at the more or less general meaning. Then I went back to certain themes and special expressions and attempted to develop their meaning, then again returned to the more global meaning of the interview or story of the mother’s shared artifact in light of the deepened meanings of the parts. This process continued until the meanings of the different parts made sensible patterns and entered into a coherent whole.

#### Construction of Validity

In this section, I will describe the various ways that I integrated validation techniques into the craftsmanship of this research study. Validation according to Kvale (1996) depends on the quality of craftsmanship during the investigation, continually checking, questioning, and theoretically interpreting findings. One way to validate findings is to adopt a critical outlook on the analysis with continual checks on the persuasiveness and plausibility of the narrative, correspondence with participants, coherence and pragmatic use of the findings.

#### *Persuasiveness and Plausibility Criterion*

“Artistic works need to be plausible and persuasive so that the viewer and reader will have a faithful portrait of the meaning the ‘artist’ wants to create” (Holloway & Freshwater, 2007, p.110). In writing persuasively, the reader

experiences "*being there*". The concept of *verisimilitude*, a literary term, captures this thinking (Richardson, 1994, p. 521).

Creswell (2007) noted that the narrative researcher should aim to write their stories and findings in ways that are clear, engaging, and full of unexpected ideas (p. 40). The story and findings become believable and realistic, accurately reflecting all the complexities that exist in real life (Creswell, 2007, p. 46).

Riessman (1993) noted that persuasiveness is greatest when theoretical claims are supported with evidence from participants' accounts and when alternative interpretations of the data are considered. This criterion forces us to document interpretive statements for the benefit of skeptical outsiders (p. 65-66). If this is successful, the research has credibility and fidelity.

#### *Correspondence Criterion*

In narrative research trustworthiness and credibility can be increased through correspondence with participants. Riessman (1993) refers to correspondence as the degree to which the participants have been fully involved in the research process and have had the opportunity to reflect on and comment on their story as retold by the narrative researcher. Any changes, concerns, or objections simply become part of the story of the research and can be included in the narrative, with review again by participants. This process is called "member checking" (Lincoln & Guba, 1985). The intent of member checking is to increase the credibility of the resulting research report by involving the participants throughout the research process (Lincoln & Guba, 1985, p. 314). I invited participants to review their transcripts and my identification of core story types and themes as well as my interpretations. Three participants chose to participate



in this process, and those three participants confirmed my interpretations of the data. I also invited transcriptionist (Rebekah Young) to participate in this process because she had transcribed interview transcripts verbatim. She also confirmed my interpretation of findings. I also shared study findings and communications with participants with my dissertation chair (Dr. Karen Saucier Lundy) and she also confirmed my interpretation of findings.

### *Coherence Criterion*

Coherence refers to the way different parts of the interpretation create a complete and meaningful picture (Lieblich, Tuval-Mashiach & Zilber, 1998, p. 173). There are three levels of coherence according to Riessman (1993). *Global coherence* refers to the overall goals a narrator is trying to accomplish by speaking. For example, the global goal in developing an account (speaking) is to describe the stories of mothers who have experienced having a child in the NICU and to describe their dominant moral concerns. *Local coherence* is what a narrator is trying to effect in the narrative itself, such as the use of linguistic devices to relate events to one another. *Thematic coherence* is evident in portions of interview text about particular themes. For example, individuals developed their narratives around a set of common themes which figured importantly and repeatedly in their narratives (Riessman, 1993, p. 67).

According to Riessman (1993), "the three levels of coherence may offer different perspectives on the same discourse problem, whereas at other times they reinforce the same perspective. But, if an utterance is shown to be understandable in terms of the three kinds of coherence, the interpretation is strengthened" (p. 67). In this study, a multi-level analysis yielded story types as

well as narrative features and transcendent themes in order to illuminate the complex and richness of findings. Global coherence was identified in the three narrative types identified as enchantment, disenchantment and re-enchantment stories. Local coherence was identified with the use of structural analysis identifying how each participant used linguistic devices to relate events to one another. Thematic coherence was identified in the common themes that participants identified in their stories. As was noted in this study, different levels of coherence offered different participant perspectives and also reinforced commonalities between participant narratives and themes strengthening the interpretation of data.

#### *Pragmatic Use Criterion*

Pragmatic use refers to the extent to which a particular study becomes the basis for others' work. The current study provides an audit trail, including the following information, to make it possible for others to determine the trustworthiness of the work: (a) clearly identifying the research questions, (b) disclosing where the research data will come from, for example, first-person accounts obtained in narrative interviews and from artifacts, (c) identifying and describing steps in the analysis of the data, (d) describing how the interpretations were produced, (e) specifying how successive transformations of the data were accomplished, (f) attending to the issue of voice in the re-storying and re-presentation of the narrative by clearly indicating who the narrator is –the researcher, the participant, both in sequential form, both in composite form, or both as interpreted and re-storied by the researcher, and (g) making primary data

available to other researchers with the consent of the participants (Riessman, 1993; Duffy, 2007).

### Risks, Cautions and Uses of Storytelling

Individuals are motivated to tell stories for a variety of reasons. However, the researcher should bear in mind the risks associated with storytelling. Holloway & Freshwater (2007) caution that the “sensitive and often intimate nature of the researcher-participant relationship, along with the personal and often complex data collected require that the narrative researcher pay specific attention to ways in which the relationship and findings could be exploited” (p. 60). In short, the researcher is affected by the participant’s stories as the participants are affected and influenced by the researcher. In this relationship it is important that the narrative researcher provide opportunities for meaningful and ethical dialogue that address issues of ultimate concern for the participants. A dialogical relationship becomes the foundation for mutual understanding and self-development for both parties (Josselson, 2007; Miller, 1996).

“Narrative analysis takes as its object of investigation the story itself” (Riessman, 1993, p. 1). The current narrative inquiry attempts to systematically study personal experiences and meanings of mothers of infants that required care NICU. Meanings and experiences were expressed in stories told in narrative interviews and in stories told about artifacts collected during the NICU course. The study also sought to examine dominant moral concerns expressed in mothers’ stories.

I limited discussion in my study to first-person accounts by participants obtained through narrative interviews and to stories mothers told about artifacts

that they collected during their NICU course. The methodological approach examined each participant's story using a multi-level analysis. In the first level of analysis the stories were read for structural and functional elements so that core narratives could be identified. The second level of analysis explored narrative features and revealed transcendent themes.

Narrative methods have particular strengths and weaknesses. "Narrative analysis is not useful for studies of large numbers of nameless, faceless, subjects" (Riessman, 1993, p. 69). Riessman (1993), described narrative analysis methods as painstakingly slow. Accordingly, the methods require attention to subtlety: nuances of speech, organization of a response, local contexts of production, social discourses that shape what is said, and what cannot be spoken (p. 70).

Riessman (1993) suggests that this method is well suited to studies of subjectivity and identity since this approach is rooted in time, place, and personal experiences and gives prominence to human agency and imagination (p.5). Additionally, narrative inquiry is also useful to examine social life and culture as viewed through an individual's story.

Narrative research is suitable for some research situations but not others. The ultimate goal of narrative inquiry is to describe stories, and learn about whole persons in context and in time. "Narrative analysis allows for systematic study of personal experience and meaning: how events have been constructed by active subjects" (Riessman, 1993, p. 70).

Josselson, Lieblich & McAdams (2003) noted that "rather than forming hypotheses, the narrative researcher frames questions for exploration; in place of

measurement are the challenges of deeply listening to others; and instead of statistics are the ambiguities of thoughtful analysis of texts" (p. 3).

As narrative analyst, the researcher does need to keep in mind that our analytic interpretations are partial, alternative truths that aim for believability, not certitude, for enlargement understanding rather than control. For this reason, the researcher must also be a narrative critic. The researcher must pay particular attention to what Connelly and Clandinin (1990), call "the Hollywood plot," the plot where everything works out well in the end (p. 10). Spence (1986) also described this process as "narrative smoothing" (p. 211). It is the process that goes on all the time in narrative both during data collection and writing. The problem is therefore a judicial one in which the smoothing contained in the plot is properly balanced with what is obscured in the smoothing for narrative purposes.

To acknowledge this process is to question and be alert to the stories *not told* as to those that are. The researcher must constantly question the selections made, the possible alternative stories, and other limitations seen from the vantage point of the critic. (Connelly & Clandinin, 1990, p. 10). Herein lies one of the great strengths and weaknesses of a narrative approach, for while stories paint pictures that create novel insight, they are subject to interpretation and investigation from all members of the community for and in which they are told (Hester, 2001, p. 58).

Clandinin and Connelly (2000) noted that as narrative researchers, we need to be aware of what others might think of our work. We need to be alert and aware both of the contexts for our work, and of the questions from field texts, and research texts from the point of view of the three dimensional narrative inquiry

space. Clandinin and Connelly (2000) refer to this awareness as *wakefulness* to the temporality, sociality and place in which narratives take place.

Wakefulness allows narrative researchers to proceed forward with a constant, alert awareness of risks, simplistic plots, scenarios, and unidimensional characters. Wakefulness is best fostered by sense of wonder and openness to diversity. Clandinin & Connelly (2000), noted that "as narrative researchers, we need to be awake to criticisms but not necessarily accepting of them" (Clandinin & Connelly, 2000, pp. 182-183).

### *Writing the Report*

Chase (1996) cautioned that all research based on in-depth interviews raises ethical and process issues, but narrative research demands that we pay special attention to participants' vulnerability and analysts' interpretive authority. Therefore, before writing the research report, it was important to understand how the researcher attempted to balance the pressures of attending to participants and claiming some degree of authority as narrative analyst.

The essence of a good qualitative research design, according to Flick (1998), turns on the use of a set of procedures that are simultaneously open-ended and rigorous and that do justice to the complexity of the social setting under study. The goals and ideals described by Chase (1996) were strived for throughout the various stages of this study, including the in-depth interviews, analysis of data and the reporting of findings:

1. Create an environment that is comfortable and collaborative.
2. Create interactive conditions that encouraged participants to tell stories fully.
3. Share work in progress as needed with participants and gain feedback

throughout the process in an effort to breakdown the barriers between researcher and participants.

4. Allow interpretations to be revised and strengthened by an interactive process.
5. Explain to participants that their stories will be preserved for their uniqueness, however, in the analysis phase of the project, the researcher may reframe their experiences by comparing and contrasting different women's experiences as part of an attempt to describe the larger social phenomenon of moral experiences that exist for mothers' in the NICU. Therefore, the interests of the researcher may differ from the interests of the participant in the analysis. For example, there may be differences in what mothers' want to articulate by storying their personal experiences and what I, as researcher, want to communicate through my interpretations.
6. The aim of this narrative analysis is not to impose unchangeable or definitive interpretations on participants' stories or even to challenge the meanings participants attach to their stories. Rather, its goal is to turn attention to taken-for-granted moral concerns embedded in the everyday practices of storytelling.
7. Discuss with participants that when there is a disagreement between researcher and participant in regards to interpretation of the interview text, that this will be noted.
8. During interviews the researcher wants to hear about the mothers' experiences fully and in detail but the researcher's analysis will reframe their stories through connections to the broader moral context.
9. Narrative analysis often requires extensive use of some and minimal use of other individual's stories.
10. When a mother's story is chosen for close analysis, the researcher will inform her and assure her that the researcher will honor her requests to change or exclude details to protect her identity. The participant will be given the opportunity to choose a pseudonym or the researcher will chose one for her.
11. Participants will not know in advance which stories will be selected for detailed analysis and which specific aspects of the broader moral context will be significant in the analysis. (pp. 59)

The researcher acknowledges that when this research is published or presented, participants are invited to read what has been written about them.

Hence, the researcher must think carefully about the impact that her continuing narrative interpretation will have on the participants. The researcher's analysis will be presented, not as a privileged account, but as conditioned by a certain perspective that should be made as explicit as possible. This leaves room for participants and readers to interpret the narrative in their own terms subsequent to publication.

Munhall (2007) noted that in qualitative inquiry, the research imperative (advancing knowledge) is key, however, a balancing act is required between the research and therapeutic imperatives (to minimize distress and do no harm). She noted that the therapeutic intention is as important as the research intention. For this balancing act to work, communication and collaboration are key (p. 222).

### Summary

I have demonstrated the processes I used to develop this narrative inquiry beginning with situating myself and my thinking about qualitative research. I have referred to my worldview central to qualitative inquiry: a worldview consistent with my assumptions and the theoretical lenses that helped shape this study including influences from hermeneutics and narrative inquiry.

I have also sought to make clear to the reader that my research questions and the methods undertaken in the study were appropriate to obtain answers to the questions posed. I believe that this research has demonstrated my capacity for inductive thinking, and for creative interaction with narrative data.

I have illustrated the relationship skills necessary to conduct narrative interviews. I have also described the types of questions posed to participants in



narrative interviews and thoroughly outlined the steps that were taken for each interview in this study.

I designed this study at every stage with the participant in mind, making every effort to protect participants from harm. However, a good interview exposes thoughts, feelings, knowledge, and experience, not only to the researcher but also to the participants. This process affects the persons being interviewed and leaves them knowing things about themselves that they didn't know-or least were not fully aware of-before the interview. Therein lies the difficulties of narrative inquiry, neither the researcher nor the participant can know, in advance, and sometimes even after the fact, what impact an interviewing experience will have or has had on them. Therefore, in this study, I identified an ethical framework for dealing with such issues.

I also showed the spectrum of approaches to text that take narrative form. I recognized that there is no single method of narrative analysis. I also recognized that regardless of their differences the examples described in this study were ways to analyze individuals recollections of the past systematically, informed by narrative theory.

As I moved to the data collection and analysis phase of this study, I endeavored to suspend the philosophical and theoretical knowledge gained throughout this process in order to approach the participants and their stories naively and openly. I sought to maintain flexibility that was open to encountering what Josselson and Lieblich (2003) call *terra incognita*, unknown lands and return to the readers with interesting and valuable stories to tell about how mothers perceive their NICU experience. (p. 272)

## CHAPTER V

### CONSTRUCTING AND MANAGING NARRATIVE TEXTS

#### Introduction

This chapter is focused on presentation of the data with analysis and interpretation. The data set from the four participant mothers is complex and various methods of presentation were considered. In an effort to best portray the richness of findings, the following order of sections will be included: (1) an introduction to participants; (2) strategies for identifying and managing data; (3) nature of interview responses; (4) examples of intact narrative exemplars or story types using poetic condensation; (4) identification of five narrative features and transcendent themes; and finally (5) interpretation of the data through the four research questions which guided the study.

#### Introduction to the Participants

I will now present brief biographical information about each of the four participants and describe stories of my work with them. In addition, I consider how these participants continually contributed to my thinking of the interpretations and presentations of the interview data. This section illuminated how the dynamics of the rapport that the participant and I created shaped the structure and content of the narratives. A feminist perspective is reflected in the attention to the relationship between my participants and me, the exploration of subjectivity and multiple identities, and the focus on ways of reacting to feelings of difference in a culture that longs for stories of progress.

*Suzie, Mother of Terrell [both pseudonyms]*

Suzie is a 20 year old, single, first-time mother. She had been at work (certified nursing assistant) when she began feeling ill. She took her blood pressure and it was elevated. Suzie then left work and went to the emergency room where she was treated with antihypertensive medication and sent home. She was to follow up with her obstetrician the next day. After a visit to her obstetrician, Suzie was tested for preeclampsia, the test was negative, indicating that she did not have evidence of preeclampsia at the time. She was sent home on bed rest with bathroom privileges only. Later that evening, Suzie was feeling better on her medication. She decided to put her baby's crib together with the help of her mother. Then she went to bed for the evening. Later that night, Suzie woke to go to the bathroom and noticed that her vision was blurred. She thought that it was because she was sleepy and she returned to bed. The following day, her siblings, arriving home from school, noticed that Suzie was still lying in bed, she was blue and barely breathing, she was covered in blood because she had nearly bitten her tongue in two during a seizure. Her brother and sister intervened, repositioning Suzie on her side and she began breathing again. Her sister phoned 9-1-1. Suzie was then taken by ambulance to a small community hospital where she was then transported by helicopter to the nearest regional referral center for emergent delivery by cesarean section for maternal indications including eclampsia.

Eclampsia, is an acute and life-threatening complication of pregnancy; it is characterized by the appearance of tonic-clonic seizures in a patient who had developed preeclampsia. Rarely does eclampsia occur without preceding

preeclamptic symptoms. Hypertensive disorder of pregnancy and toxemia of pregnancy are terms used to encompass both preeclampsia and eclampsia. The only known cure for eclampsia is delivery of the baby. Suzie was only 30 weeks along in her pregnancy when Terrell was delivered.

For our interviews, Suzie chose to meet with me at my home even though that meant that she would have to drive approximately 60 miles round trip. It was difficult to coordinate a schedule for our meetings because Suzie was an extremely busy working mother. We met on three separate occasions at Suzie's convenience. Sometimes, her baby Terrell would join us. Several times we had to reschedule our meetings due to conflicts in Suzie's work schedule, the needs of the baby or transportation difficulties. However, Suzie was always thoughtful and phoned me in advance if there was a problem, to tell me that our meeting would need to be rescheduled. When we met, our meetings were held in my home office, where Suzie shared her story. Suzie also shared memorabilia from her NICU experience following our first interview. Her memorabilia included: photographs, crib cards, mementos from her baby shower, card and letters from her family, and items from Terrell's NICU course. Terrell was in the NICU for 29 days.

*Raelee, Mother of Owen [both pseudonyms]*

Raelee is a 29 year old, married, first-time mother and is a kindergarten teacher. At the time of our interview, she was working part-time and enjoying spending more time at home with Owen. She had been vacationing on the Gulf Coast when she noticed vaginal bleeding. She phoned her obstetrician who was several hours away and she suggested that Raelee go to the emergency room,

just to have things checked out. As her husband drove her to the hospital, Raelee began having abdominal pain. When she arrived at a small community hospital near the beach, she was told that she had an incompetent cervix and ruptured membranes. Owen was delivered by cesarean section. Owen was 26 weeks gestational age. While Raelee's delivery was in progress, a transport team from a regional referral center was in route to pick up Owen, Raelee was told that Owen would need care in a different hospital with a level III NICU. When the transport team arrived, Raelee was allowed a brief look at Owen before he was flown by helicopter to the regional referral center about two hours away. Mother and baby would be separated in two different hospitals for two days.

Once Raelee was released from the hospital, she traveled to the regional referral center where Owen was hospitalized. Her experience was compounded by the nearly 150 mile distance between her home town and the hospital where Owen would live for the next several months. Raelee's sister lived near the regional referral center and Raelee stayed with her for the months that Owen was in the hospital. Raelee only made a few brief trips home while Owen was in the hospital.

For our first two interviews, Raelee preferred that we meet in her home town, which was about a two hour drive from my home. She agreed to meet with me over two consecutive days, since I was staying in a hotel near her home. When asked if she would like to meet at her home, a restaurant or the hotel, she said she would meet me at my hotel. Our first two interviews took place at a little desk in my hotel room. Our third interview took place in the conference room at the regional referral center, a place that was convenient for both of us, as Raelee

was in town visiting with her sister and she wanted to bring Owen to visit his doctors and nurses at the NICU. Owen joined us for our third interview.

During our first meeting, Raelee shared her story with me and she also shared some of the memorabilia that she had collected from her NICU experience including her: photo album, journal, mementos from the NICU, and her baby's web site. In subsequent interviews, Raelee elaborated on her story. Owen was in the NICU for 122 days.

*Abbey, Mother of Carlyn [both pseudonyms]*

Abbey is a 27 year old, married, first-time mother. Abbey works as a store manager and occasionally helps her husband at the coffee shop he owns. She began having low back pain while at the coffee shop. Fearing that she might be in labor, she had her husband drive her to the regional referral center emergency room. Upon arrival, Abbey was transferred to the obstetric unit where she was noted to be having contractions and hypertension. An ultrasound was obtained to check the status of the baby. Doctors noticed the baby was having decreases in heart rate with Abbey's contractions. Abbey was hospitalized overnight for observation. The following day, Abbey was admitted due to her continued hypertension and the baby's intolerance to her labor. Abbey was scheduled for a cesarean section. The NICU team was asked to attend the delivery. Carlyn was born at 37 weeks gestational age. She did not have any breathing or heart problem and was a pink baby with a vigorous cry. However, the NICU team noticed that Carlyn was shaking shortly after delivery and a blood glucose test was obtained; Carlyn was noted to have hypoglycemia. Abbey was given a bottle and offered a feeding to Carlyn, but her blood sugar did not improve; she was

admitted to the NICU for treatment of her hypoglycemia with IV glucose administration.

Abbey chose to have all three interviews at the coffee shop that she and her husband owned. We met at her convenience, as she too was a very busy working mother. It was common during our interviews to be interrupted, depending on the flow of customers through the coffee shop. Various coffee shop noises could be heard in the background of our interview transcripts.

During our first interview, Abbey told the story of her experience and also shared her NICU memorabilia including: photographs, memento's from the NICU, Carlyn's medication bottles, her emergency syringes, the record of Carlyn's blood glucose tests that she documented for the endocrinologist, as well as her glucose testing kit. Carlyn was in the NICU for 13 days.

*Elizabeth, Mother of Jay [both pseudonyms]*

Elizabeth is a 27 year old, married, first-time mother and an administrative coordinator. At the time of our interview she was a stay at home mother for Jay. Elizabeth was admitted to the hospital in labor, where she received a Pitocin induction. She delivered Jay at 39 weeks by vaginal delivery after a long labor with forceps extraction. Jay was pale in the delivery room, but his color and activity improved shortly after birth. Jay had bruising to his head and a conjunctival hemorrhage, but otherwise he was breathing well and was swaddled and placed in Elizabeth's arms moments after delivery. Her family took photographs and Elizabeth was able to give Jay his first feeding. He was then taken to the newborn nursery. A few hours later, the nursery nurse told Elizabeth

that she did not like the way that Jay was breathing and was having him transferred to the NICU for closer observation.

Upon arrival to the NICU. Jay was noted to have seizure activity. He received a dose of Phenobarbital, an anti-seizure medication, and was schedule to have a Magnetic Resonance Imaging (MRI) of his brain. His MRI revealed a subdural hematoma and the neurosurgeon was called. Soon afterwards, Jay had surgical placement of a ventriculostomy to relieve the increased intracranial pressure that was causing his seizures.

Elizabeth chose to have our first two interviews in a conference room at the hospital where Jay was born. The conference room was just outside the NICU. Our third and final interview took place at Elizabeth's home. We sat comfortably at her kitchen table while Jay was sleeping down the hall in his room. The interviews were scheduled at Elizabeth's convenience. In our first interview, Elizabeth was encouraged to tell her story. Following the first interview, Elizabeth shared her photo album with me. After our third interview, Elizabeth shared more photographs and Jay's box of NICU memorabilia including mementos like crib cards, Jay's blood pressure cuff, the level from Jay's ventriculostomy equipment, a scrapbook of Elizabeth's pregnancy including ultrasound pictures, and records of doctor's appointments, etc. Elizabeth also told me about the letters she and her husband wrote to Jay before he was born.

Later, when Jay woke from his nap, I got to meet him and I had the opportunity to tour his nursery. Jay's beautiful, brightly lit room overlooked the backyard with lots of colorful flowers and a tree just outside his window with birds eating from a bird feeder. His room was decorated in a surfer theme. Jay's family



loved to spend time out doors and at the beach, his dad enjoys surfing, and his room reflected this interest. Elizabeth had painted a gorgeous mural on the nursery wall of a beach scene. The memorabilia and photographs that Elizabeth shared represented her pregnancy, birth and the 21 days that Jay was in the NICU.

### Strategies for Identifying and Managing Data

The experience that participants had in common was that they were all mothers who experienced the NICU after the birth of their first baby. Each participant offered differing perspectives of her NICU experience and exercised individual strategies for resolving her feelings of being different from normal mothers. To foreground the participants' viewpoints in subsequent chapters, I provide extensive interview data that allowed the participants to speak for themselves. My voice is heard through the selection of the data that is represented.

Each participant was given an opportunity to select a pseudonym during the interview process. If a pseudonym was not identified by the participant, one was selected for her: Suzie, Raelee, Elizabeth and Abbey. Each participant was distinctive in her motivation to participate, circumstances that led to her NICU experience, length of time spent in the NICU, and the difficulties encountered throughout the NICU experience. However, they shared a passion to assist care providers in better understanding mothers' experiences and in their desire to facilitate improvements in care for future NICU mothers.

The data set from the four participant mothers is complex and various methods of presentation were considered. In an effort to best portray the

richness of findings, the following order of sections will be included: (1) a description of the nature of the interview responses and narratives related by the participants; (2) intact narrative exemplars or story types; (3) identification of the five narrative functions and its transcendent themes; and (4) interpretations of the data through the four research questions which guided the study will be interspersed throughout this chapter and the final chapter

1. What core narratives are told by mothers who have had the experience of having a baby in the neonatal intensive care unit (NICU)?
2. What do the stories reveal about the mothers' search for meaning in the NICU experience?
3. What moral concerns are revealed in the mothers' stories?
4. How might mothers' stories be viewed to improve care providers understanding of what is most common, most taken-for-granted and what concerns mothers' most so that quality care can then be provided?

#### Nature of Interview Responses and Narratives

For this study, a narrative was defined as a discrete story of personal experience characterized by temporal ordering of events with a recognizable beginning, middle and end structured around a plot that had a point or moral that the speaker wants a listener to take away from the story (Polkinghorne, 1988; Riessman, 1993, 2008). To facilitate narrative accounts, participants were encouraged to recall the story of their NICU experience in as much detail as possible, beginning wherever they liked. Their responses took a variety of forms. Some participants provided lengthy narratives in response to the first interview

question and some provided data that answered additional research questions in responses that did not necessarily take a narrative form (question/answer exchanges, reports, arguments).

These non-narrative responses were generally short and provided insight into the general experiences of NICU mothers. Consequently, to fully describe the mothers' experiences, a thematic analysis of responses was conducted in addition to the analysis of the narrative segments. While the themes are described separately, the narratives often contain examples of how some themes could be interwoven and elaborated as the stories unfold. Although several narratives exemplify certain themes, no one narrative is representation of, or reflects all of the themes and sub themes. In addition, some narratives offer distinct experiences that are not reducible to themes.

Multi-level analysis was performed for the current study. The first level of analysis looked at participant narrative individually and as a group to identify core narratives using structural approaches guided by Labov and Walestzsky (1997) and Gee (2005). The second level of analysis identified narrative features and transcendent themes drawing on approaches outlined by Charon (2006). I have outlined the steps taken in the current narrative analysis (see Table 2).

Table 2.

## Steps in Narrative Analysis

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<b>Steps in Narrative Analysis</b>	
1.	<i>Listened to audio taped interviews and read verbatim transcripts multiple times.</i>
2.	<i>Encouraged participants to read verbatim transcripts for accuracy and to provide comments (three out of four participants took part in this process).</i>

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<b>Structural Analysis</b>	
3.	<p><b>Identified Core Narratives (General Responses)</b></p> <p>Enchantment Stories</p> <p>Disenchantment Stories</p> <p>Re-enchantment Stories</p>
4.	<p><b>Poetic Condensation (Structural properties/frames/parts/meanings)</b></p> <p>Verbatim transcripts were condensed to poetic stanza's (groups of lines said together about a single topic) using techniques of Gee (2005) and Riessman (1993; 2008). Each stanza represented a particular perspective or image.</p>
5.	Encouraged participants to read my interpretations of core narratives and provide comments/validation of findings (three out of four participants took part in this process).
6.	Encouraged participants to read my interpretations of poetic condensation and provide comments (three out of four participants took part in this process).

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<b>Thematic Analysis</b>	
7.	<p><b>Identified Narrative Features and Transcendent Themes</b></p> <p>Narrative Feature: Causality/Contingency</p> <p>Tears in the fabric of every day life</p> <p>Mourning a life as it was imagined</p> <p>Questions of Why?</p> <p>Search for Answers</p>

**Table 2 (continued).****Narrative Feature: Temporality****Rollercoaster****Waiting****Baby jail or Petting zoo?****Narrative Feature: Singularity****Tailored Care****Assembly Line****Desire for Normalcy****Prior Experience with Illness and Death****Narrative Feature: Intersubjectivity****Encounters with Others****Out of the Loop****Earned Trust****Butterflies and Curtains****Protecting Family****Family Support****Narrative Feature: Ethicality****Valued Responsiveness****Vulnerable Aspects of Life****Demonstrating Hope and Faith****Desire to Help Others**

8. Encouraged participants to read my interpretation of narrative features and transcendent themes to confirm accuracy and provide comments (three out of four participants too part in this process.

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**Note:** One participant chose not to participate in the validation process due to time constraints and because of family crises unrelated to her baby.

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## Core Narratives

Analysis of data began after first listening to and then reading verbatim transcripts repeatedly. As one strategy for data identification and management, I selected key aspects of large segments of transcript and identified narrative exemplars (Riessman, 2008). Following Riessman's approach, I adapted Labov and Waletzky's (1997) definition of narrative as a description of past events with a sequence of temporal order. Each clause has a specific social function that matches the temporal sequence of reported events (Chase, 2005). This framework helped me to see how these narratives were organized and functioned before beginning the thematic analysis (Riessman, 2008). I used the sociolinguistic features that Labov and Waletzky developed for oral narratives (see Table 3).

Table 3

### *Explanation of Labov and Waletzky's Elements of Narrative*

Narrative Structural Elements	Meaning/Function
Abstract	Summarizes the point of the narrative (optional)
Orientation	Orients the listener in respect to time, place, situation, participants, behavioral situation
Complicating Action	Describes sequence of actions, turning point, crisis, problems
Evaluation	Illuminates the meaning of the complicating action
Resolution	Reflects how the action was resolved. Describes how the plot is resolved.
Coda	Ends the narrative; returns listener to present (optional)

At the beginning of the first interview I made the following statement to participant mothers:

I would like for you to tell me the story of your NICU experience, all the events and experiences that were important to you up until now. Start wherever you like. Please take the time that you need. I'll listen first, I will try not to interrupt while you share your story with me.

The multi-level analysis of the narrative data yielded three story types organized around the central plots of (1) enchantment; (2) disenchantment and; (3) re-enchantment. However, participants did not necessarily bring the core narratives up in the order that I have listed them here. To illuminate the personal, emotional content of the exemplars and allow the reader to enter into the situation, narrative exemplars will be presented using stanzas organized into scenes as suggested by Riessman (2008) and adapted from Gee (2005). Coding of the narratives using Labov and Waletzky's (1997) structural method is indicated in italics employing the following abbreviations: abstract (AB, optional); orientation (OR); complicating action (CA); resolution (RE); evaluation (EV); and coda (CO, optional).

Turning to my selection of Raelee's account of her NICU experience, I provided an example of how verbatim transcripts were condensed to poetic form. Table 4 (see page 174-176) displays two representations. The left side of the table shows the original transcription, which I have parsed into clauses (Riessman, 1993, 2008). In this version, I have included all my utterances as interviewer, and have maintained the participant's false starts, break-offs, and expressive sounds and silences or pauses. On the right side of the table is my reduction to a core narrative, which includes Labov and Waletzky's (1997) structural elements and provides a skeleton plot. I identified parts of the narrative

by their function. To maintain focus on the core narrative, I excluded pauses, repeated words, and non-lexical expressions. A long string of events may actually consist of several complicating actions as is shown in this narrative. (Labov & Waletzky, 1997) and I have identified six complicating actions in this narrative segment.

### *Enchantment Stories*

Many women, like the four women in this study, grow up dreaming of being mothers. Once they become pregnant their mind is filled with dreams, aspirations, goals and plans for their pregnancy, birth and baby. These are the types of stories that I have identified in this study as *enchantment stories*. In narratives of enchantment, mothers discussed their hope, dreams and ideals for their first pregnancy, birth and baby.

#### **Suzie, mother of Terrell Enchantment Story**

##### *Plan for natural birth*

He was my first baby

I always wanted a natural birth

With no medications

All natural

AB

And just be able to hold him

As soon as he came out

And be able to love on him

And kiss him

And tell him how much I loved him

OR

##### *Plan for water birth/special moment*

I wanted a water birth

To be able to get in the whirlpool and relax

And have my mom and everybody in the room

And just to have that special moment.

CA

##### *Plan for the picture perfect family*

I've always wanted the picture perfect family

Mom, dad and kids

CA



Not having a baby before we're wed  
But that happened

*He wasn't planned but he is not a mistake*

So that is the case

He wasn't planned

But he is not a mistake

That's the way I look at it.

CA  
EV  
RE

**Raelee, mother of Owen  
Enchantment Story**

*I always wanted to be a mom*

I wanted a child for a long time

I've always wanted to be a mom

Since I was little

That's what I wanted to do was be a mom

AB

*Pregnancy not planned but happy to be pregnant*

When I found out I was pregnant

We were shocked

Because it wasn't planned

But I was so happy that I was pregnant

CA  
EV

*Pregnancy didn't show for five months*

And me, having a small body size,

I couldn't tell I was pregnant

Until I was five months pregnant

That's when I started wearing maternity clothes

And that was so exciting

OR  
CA

EV

*Starting to show/looked forward to gaining weight*

For Christmas, I got maternity clothes

I was so excited to wear them

I was looking forward to gaining the weight

And being pregnant

OR  
EV

*My goal was to have a natural childbirth*

I loved it when people would say "you're pregnant"

That was wonderful

And so I was looking forward to it

My goal was to have a natural childbirth.

RE

**Elizabeth, mother of Jay  
Enchantment Story**

*Normal Pregnancy*

My pregnancy went totally normal  
Everything was fine  
I never felt better in my life  
It was wonderful

AB

*We were healthy*

I was healthy.  
I was normal  
He was healthy and normal  
He was a perfect weight

OR

*Everything was fine*

Everything was fine  
It was totally fine

EV

*We had it planned out*

When you get pregnant  
And after we found out it was a boy,  
You kinda have it planned out.

CA

*He would play soccer like his dad*

He'll play soccer with his dad,  
His Dad's a soccer player  
And he'll do that

RE

**Abbey, mother of Carlyn  
Enchantment Story**

*I had expectations*

I had expectations  
My water would break somewhere,  
The bathroom, the kitchen, Wal-mart [laughs] wherever,  
And they'd [say], "Okay. It's time to go to the hospital."  
And we'd call everybody and my family.

AB

CA

OR

RE

All four participant mothers in interviews talked briefly about their hopes, dreams, plans, and expectations for their first pregnancy, birth and baby. Suzie hoped that she would get married before having a baby; she had planned to have

a natural birth experience that would result in a picture perfect family with mom, dad, and baby.

Raelee had always wanted to be a mother. However, she was shocked when she found out that she was pregnant because the pregnancy was not planned, but she was very happy to be pregnant. She looked forward to gaining weight so that everyone could tell that she was pregnant. She looked forward to wearing maternity clothes, but with her small body frame she didn't start to show until she was five months pregnant. At Christmas, she purchased maternity clothes and she was very excited to finally be showing a pregnant belly. She loved it when people would recognize her pregnancy and she looked forward to a natural childbirth.

Elizabeth had been married for years, she dreamed of being a mother. She took care of herself, was healthy and the baby was healthy during the pregnancy. When she found out that she was having a baby boy, she dreamed of him playing soccer like his dad. She had it all planned out.

Abbey, had expectations for her pregnancy, she thought she would be somewhere like Wal-mart, the bathroom or kitchen and her water would break and everyone would excitedly say, "It's time to go to the hospital" and she and her husband would begin calling family and friends to welcome the new arrival.

Layne (2003) noted that "the preferred American narrative structure informs the stories we tell about the proper and expected trajectories of individual lives." (p. 67). Mothers often believe that if they eat healthy, go to prenatal checkups, exercise, and attend birthing classes, that their pregnancy, birth and

baby will stay on a predictable, coherent, linear path and they will be rewarded with the healthy Gerber baby.

Television shows like TLC's "Baby Story" and "Bringing Home Baby" project the American ideal of mothers and babies staying on their expected paths. In A Baby Story viewers are allowed an intimate and emotional journey as they get a voyeuristic peek of couples' experiences from the final weeks of pregnancy through the dramatic labor and the joy of the unforgettable birth to the first weeks of a new life. "Bringing Home Baby" is another TLC's series that focuses on those first 36 hours at home with a couple's new baby. The media perpetuates the fairy tale.

Birthing classes cover all kinds of issues surrounding childbirth including breathing techniques, pain management, vaginal birth, and cesarean birth. They are intended to help prepare expectant mothers for the many aspects of childbirth: for the changes that pregnancy brings, for labor and delivery, and for parenting once the baby is born. Typically, new parents take birthing classes during the third trimester of the pregnancy, when the mother is about 7 months pregnant. But there are a variety of different classes which begin sooner.

One participant (Elizabeth, mother of Jay) in this study said that she watched "too much" of "Baby Story" and "Bringing Home Baby;" she also attended birthing classes. However, these television shows and birthing classes do not prepare mothers when the birth plan goes sour and the baby ends up in the NICU. They often create the enchanted fairy tale as certainty, romanticizing the childbirth experience as idealized reality.

### *Disenchantment Stories*

What then happens when the mythologized dream of motherhood takes an unexpected turn? More often than we would like to imagine, plans for pregnancy, birth and baby are shattered. The next story type that was identified in the current study was stories of *disenchantment*. *Disenchantment stories* were told by participant mothers when things did not go as planned and their babies required care in the NICU for a period of time. These stories were about the NICU as foreign, surreal, scary, overwhelming and not normal—a land far, far away from the fairy tale dream of ideal motherhood. These stories describe a breach between the ideal and real. They describe tensions between the needs of the mother and the actions of care providers.

#### **Suzie, mother of Terrell Disenchantment/Birth Story**

*Everything went fine until...*

Okay, my pregnancy

Got pregnant on October the 19<sup>th</sup>

And everything went fine until May 11<sup>th</sup>

AB

*Elevated blood pressure*

That night, I was at work

Playing with a blood pressure cuff

And I tested my blood pressure

And it was 150/80

CA

*Preeclampsia stage*

And they told me to wait a little while

And recheck it again

Just to make sure everything was okay

It was 190/119

So, I was going into the preeclampsia stage

OR

CA

*Emergency room visit*

And I went

They sent me from work

straight to the emergency room.

My mom came into town

OR

And picked me up

*Meds, doctors appointment, sent home*

When we got there

They gave me some blood pressure medicine

CA

And sent me home

They made me a doctor's appointment

*Sent home on bed rest with bathroom privileges only*

Went to the doctor on Wednesday

He tested me for toxemia

Came back negative.

He put me on bed rest

CA

With bathroom privileges only

*I did something I wasn't suppose to*

That Wednesday afternoon

I did something I wasn't suppose to

CA

I put the crib together.

Then I went to bed.

*Blurred vision*

I got up about 1'oclock am

And went to the restroom

And my vision was really blurry

And really off

OR

It was probably five, six inches off, then usual

I was reaching for something on the left

And it was way on my right.

*Went back to bed*

So, then I went back to bed.

OR

I remember falling back in the bed

And I don't remember anything until Friday afternoon

When my mom told me that I had to have a C-section

*Seizures*

During the time that I don't remember

I was told that I had many seizures

And I had bit my tongue almost in two.

CA

It was swollen

*Brother and sister found me*

Then my brother and sister

Got home off the school bus

And found me in bed

OR

Laying there with nothing on but a t-shirt

And I was completely out of it.

*Blue and not breathing/near death*

I had turned blue by that time and stopped breathing  
My brother turned me on my left side  
and then I started breathing again.

CA

I had gasped for air

And so, then they called 9-1-1.

I was combative

EV

My sister called 9-1-1

*Transported by ambulance to hospital*

OR

And [paramedics] rushed me in the ambulance

To the hospital

They [paramedics] had to stop

OR

half way between my house and the hospital

Because I was having another seizure

Trying to get me stabilized

She was trying to give me IV's

And I just kept pullin' 'em out,

Rippin' 'em out

And very combative.

EV

*Transported by helicopter to regional referral center*

And then as soon as they got me to the hospital

OR

They told my mom that they needed to life flight me

To the regional referral center

If they didn't do an emergency c-section

They were going to lose both of us.

EV

*Aunt said goodbye on the helipad*

So, my aunt came up

Came by to check on me

OR

Because she had gotten a phone call

And she walked up to the top of the roof

*Aunt says goodbye*

And she told me,

She looked at me and they said "Are you family?"

And she said, "yeah, she's my niece"

OR

And they said, "well, you need,

Do you want to tell her goodbye?"

*Last time to see me/Fear of loss*

And she said tears just started running down her face

Because It [might] be the last time she would get to see me

EV

And she told me that she loved me

And I told her I loved her too

But I looked like  
I looked at her like I didn't even know who she was

*Kidney failure/ Airways closing*

And so, by the time they got me to the regional referral center  
The doctors came in the emergency room  
And went and checked me out  
And they told me that they're gonna have to take the baby  
My airways were 50-75 percent closed up.  
My kidneys had already started failing.

CA

*Premature delivery by C-section*

And then  
They went in and they got the baby  
And it was probably 10-15 minutes later  
They came back out and said everything was gonna be alright.

CA

OR

RE

**Suzie Mother of Terrell  
Disenchantment Story/NICU**

*Swept Away/Mother/Baby separation*

And then they got me stabilized  
And then they put me in ICU room  
And then they took Terrell down to the NICU

CA

*Mother visited Terrell and sat with me in ICU*

And my mom got to go in and see him  
And touch him  
And then she came back and sat with me all night.

OR

*Family visit/moved out of ICU*

So then when I actually remember some things on Friday  
I have a bunch of my family in to see me and the baby  
And check on us  
And then I got moved out of the intensive care room  
Down to a regular room

OR

*First Visit/Fear of loss*

And I didn't get to go down to see Terrell  
Until Saturday night.  
And then after that I touched him and I started crying  
Because I was scared that he wasn't going to make it  
Because he had all these tubes and IV's hooked up to him.

EV

*Reassurance from the nurse*

And then the nurse reassured me  
That he's doing really well  
And they would be starting tube feedings soon

OR



He'll be out of here in no time.

*It went pretty good*

So, it went pretty good

And then I went down there [to NICU]  
almost every time unless I was asleep

EV

*Separation at mother's discharge*

And then I stayed in the hospital until that following Tuesday  
And they discharged me.

CA

*Difficulty visiting*

Of course, me living ~ 40miles away  
And riding back and forth everyday was hard  
But I did it

OR

EV

And it was hard for me to leave him there the first time  
When I had to go home  
and tell him goodbye  
that I wasn't going to take him home with me.  
It was real hard.

EV

*Liquid Gold/ Home at 29 days of age*

Then I went up there everyday  
And I did the breast milk  
And so he got the good stuff  
And he got pretty much completely healthy  
And I got to take him home almost exactly a month later.  
It was one day shy of a month.

RE

CO

***Raelee, mother of Owen***  
**Disenchantment Story/Birth/NICU**

My son was premature  
He was 26 weeks  
We were on vacation at the beach  
When it happened  
So I was away from my doctor

AB

*Premature Birth*

We went to the hospital  
where I delivered

CA

*Infant transport*

And the air transport team  
from the regional referral center  
picked him up  
They took him back

OR

to the regional referral center

*Separation*

I stayed in the hospital  
a couple of days later  
So I didn't get to see him  
Until two days after Jamie [my husband]  
Got to see him

CA

*Not knowing what to expect*

It was all kind of nerve racking  
I just didn't know what to expect  
When I think of people being six months pregnant  
Like I was  
I'm thinking the baby's not formed  
He's missing arms or legs  
He's missing  
He's not going to look like a baby

EV  
CA  
OR

*First Visit/Afraid to see him*

And I remember going into the NICU  
and thinking, I really don't want to see him  
I didn't know what to expect  
I was very nervous going in  
And when we got there  
He was way in the back in 3C  
and I remember seeing his little incubator  
and the nurse was standing beside him  
And so was the doctor

EV  
CA  
EV  
  
OR

*Bombarded with information*

and before I even got to see Owen  
The doctor was standing there  
And telling me about his patent ductus arteriosus (PDA)  
And things that could be wrong with that  
And ways he could fix it

OR  
  
CA

*Raelee is in physical and emotional pain*

And me being in the situation I was in,  
I don't even remember what he was saying  
I was just nodding my head  
Yes, no, whatever

CA  
EV

*Attempts to inform, simply overwhelmed*

He [the doctor] was very gentle  
Making sure I understood  
But at the time I didn't know it  
But I didn't understand at all

EV

*He was perfectly formed!*  
 So then I got to see Owen  
 And He looked like a baby  
 I couldn't believe he looked like a baby OR  
 But he was so, so very little EV

*Offers to touch invoked fear*  
 The nurse said, "I'll let you touch him" CA  
 I just kept telling her, "no, no, no"  
 "No, I don't want to touch him" EV  
 "I don't want to touch him" OR  
 I just want to sit here

*Expectations gone awry/Mourning life as imagined*  
 And for the first hour or two EV  
 All I did was cry at his bedside  
 I didn't know what else to do  
 I mean, nobody goes into a pregnancy thinking CA  
 my baby's going to be premature

*Surreal/A dream/Wake up*  
 It was all so surreal to me EV  
 It wasn't really happening  
 I just kept thinking, "Wake up.  
 You're in a dream. Wake up"  
*Machines alarming/sensory overload*  
 After a while, OR  
 sitting there  
 and machines going off CA  
 the whole atmosphere  
 was a little too much for me EV

*With time, it got better*  
 But after I sat for a while OR  
 and got my thoughts together  
 I was a little better EV  
 But I still didn't want to touch him.  
 I didn't want to have anything to do with him

*Nurse encouraged and informed*  
 Our nurse was very nice about it  
 She told me, that one day I will [want to touch him]  
 She tried to do things OR  
 To keep me informed

*Placing uneasy trust in strangers*  
 With the machines going off all the time

She [the nurse] said, "if I don't get up,  
don't worry about it."  
"He's fine"

CA

*It's all so difficult to understand*  
And it's just so much at the beginning  
that you don't understand  
I didn't understand his ventilator  
I never understood  
what they were telling me

EV

*Placing faith in care providers to save him/ending unclear*  
I just said, "do whatever you gotta do to keep him"  
That's all I wanted

RE

*The first month was the hardest/mourning*  
And then I left  
And the next day came back  
And it was a little better  
I think for about the first month  
Going to the NICU  
I never once went in without crying  
Or went out without crying.  
It was the same thing [everyday

CO

Table 3

Comparison of Verbatim Transcription and Poetic Condensation  
Raelee's Disenchantment Story

Raelee's Verbatim Transcription	Raelee's Poetic Condensation/Core Narrative	
<p>I: This is interview #1 with (R.) and today is 8-19. [Umm] R. I'm just gonna ask you to tell your story of your NICU experience in whatever way you want. Begin wherever you want. I'll try not to interrupt. [Umm] I'll just maybe take a few notes [umm] for the next time that we meet I can ask you a few questions then.</p> <p>R: Okay.</p> <p>I: So, we can begin.</p> <p>R: [Umm] Well, my son was premature, of course, he was 26 weeks, [umm] we were on vacation at the beach when it happened and so, I was away from my doctor.</p>	<p>My son was premature he was 26 weeks we were on vacation at the beach when it happened I was away from my doctor.</p>	AB
<p>[Umm] We went to [REDACTED] where I delivered</p>	<p><i>Premature Birth</i> We went to a hospital where I delivered</p>	CA
<p>[umm] and the [umm] Air Transport team from [REDACTED] came and picked up him up. They took him back to [REDACTED].</p>	<p><i>Infant transport</i> and the Air Transport team from the nearest Regional Center came and picked up him up. They took him back to the regional referral center.</p>	OR
<p>I stayed in the hospital [umm] a couple of days later [umm] so I didn't actually get to see him until [umm] I think two days until after Jamie got to see him, my husband.</p>	<p><i>Separation</i> I stayed in the hospital a couple of days later I didn't actually get to see him until two days after Jamie [my husband] got to see him</p>	CA
<p>[Takes breath] [Umm] It was all kind of nerve racking [umm] cause I just didn't know what to expect [umm] when, you know, I think of people being six months pregnant, like I was, [Pause-1 second] you know, I'm thinking baby's not formed, you know, he's missing arms or legs or, you know, he's missing, he's not gonna look like a baby.</p>	<p><i>Not knowing what to expect</i> It was all kind of nerve racking I just didn't know what to expect when I think of people being six months pregnant like I was I'm thinking baby's not formed he's missing arms or legs or he's missing,</p>	EV CA  OR

Table 3 (continued).

Comparison of Verbatim Transcription and Poetic Condensation  
Raelee's Disenchantment Story

Raelee's Verbatim Transcription	Raelee's Poetic Condensation/Core Narrative
<p>and [umm] before I even got to see Owen, Dr. [redacted] was standing there and telling me about his PDA and, and things that, you know, could be wrong with that and, and ways that he could fix it and that kind of stuff.</p>	<p>he's not gonna look like a baby.</p> <p><i>Bombarded with Information</i> and before I even got to see Owen OR The Dr. was standing there and telling me about his PDA CA and things that could be wrong with that and ways that he could fix it.</p>
<p>And, of course, me being in the situation that I was in, I don't even, you know, remember what he was saying and I was just nodding my head, yes, no, whatever,</p>	<p><i>Raelee is in physical and emotional pain</i> And me being in the situation that I was in, I don't even remember what he was saying EV and I was just nodding my head yes, no, whatever</p>
<p>you know, he [the doctor] was very gentle and, you know, making sure I understood but at the time I didn't know it, but I didn't understand at all.</p>	<p><i>Attempts to inform, simply overwhelmed</i> He [the doctor] was very gentle EV making sure I understood but at the time I didn't know it, but I didn't understand at all</p>
<p>But [umm] so then I got to see Owen and [umm] [Pause-1 second] he looked like a baby. I couldn't believe how he looked like a baby, but he was so, so little</p>	<p><i>He was perfectly formed!</i> so then I got to see Owen OR and he looked like a baby. EV I couldn't believe how he looked like a baby but he was so, so little</p>
<p>I just kept telling, you know, the nurse was like "I'll let you touch him" and no, no, no, I was just like "No, I don't wanna touch him. I don't wanna touch him. I just wanna sit here."</p>	<p><i>Offers to touch invoked fear</i> the nurse was said, "I'll let you touch him" OR and I just kept telling her no, no, no "No, I don't wanna touch him. I don't wanna touch him I just wanna sit here."</p>
<p>And so for like the first hour or two, I, you know, all I did was cry at his bedside because I didn't know what else to do, I mean, you know, who, nobody goes into a pregnancy thinkin', you know, my baby's gonna be premature,</p>	<p><i>Expectations gone awry/Mourning life as imagined</i> And for the first hour or two all I did was cry at his bedside EV because I didn't know what else to do I mean nobody goes into a pregnancy thinking my baby's gonna be premature</p>
<p>I guess, and so, it was all so, you know, surreal to me, it wasn't really happening. I just kept thinkin', "Wake up. You're in a dream. Wake up."</p>	<p><i>Sureal/A Dream/Wake Up</i> it was all so surreal to me it wasn't really happening. I just kept thinking; "Wake up. You're in a dream. Wake up."</p>

Table 3 (continued).

Comparison of Verbatim Transcription and Poetic Condensation  
Raelee's Disenchantment Story

Raelee's Verbatim Transcription	Raelee's Poetic Condensation/Core Narrative
<p>After a while, you know, sittin' there and I guess the machines goin' off, just the whole atmosphere just, was, you know, a little too much for me.</p>	<p><i>Machines alarming/sensory overload</i>            After a while OR            sitting there            and the machines going off CA            the whole atmosphere            was a little too much for me. EV</p>
<p>But after I sat for a while and kinda got my thoughts together, you know, I was a little better. [Umm] But I still didn't want to touch him. I didn't want to have anything to do with him.</p>	<p><i>With time, I got better</i>            But after I sat for a while OR            and got my thoughts together            I was a little better.            But I still didn't want to touch him. EV            I didn't want to have anything to do with him.</p>
<p>Our nurse was, you know, very nice about it and, you know, tell me that one day I will, it'll be fine, you know, she tried to do things to, you know, keep me informed,</p>	<p><i>Nurse encouraged and informed</i>            Our nurse was very nice about it            She told me, that one day I will [want to touch him]            it'll be fine            she tried to do things            to keep me informed OR</p>
<p>[umm] the big things, you know, with the machines goin' off all the time and she's like, "If I don't get up, don't worry about it." And she's like, "He's fine."</p>	<p><i>Placing uneasy trust in strangers</i>            with the machines going off all the time CA            she's said, "If I don't get up            don't worry about it."            "He's fine."</p>
<p>[Umm] And it's just so much at the beginning that you just don't understand [umm] you know, I didn't understand the ventilator when they were comin' in and tellin' me, you know, "He needs this and this" and whatever else he needs, you know, I never understood what they were really telling me. [Umm] I just was like "Just do whatever you gotta do to keep him," you know, that's all I wanted.</p>	<p><i>It's all so difficult to understand</i>            And it's just so much at the beginning EV            that you don't understand            I didn't understand the ventilator            I never understood            what they were really telling me.</p>
<p>[Umm] I just was like "Just do whatever you gotta do to keep him," you know, that's all I wanted.</p>	<p><i>Placing faith in care providers to save him/unclear unclear</i>            I said, "Just do whatever you gotta do to keep him,"            that's all I wanted. RE</p>

**Elizabeth, mother of Jay  
Disenchantment**

*First Baby*

When we got to the hospital  
Everything started to seem rushed to me AB  
Maybe because it was my first,  
This was my first baby.

*Epidural/ Things happening fast*

But things just started happening quickly.  
I got the epidural almost two to three hours CA  
After I'd been admitted  
I guess because it started to get busy. EV

*Induction*

I was induced. CA  
And I don't really know why.  
I guess,  
I don't know if it was for a doctor's schedule or what EV  
He said everything would be fine with the induction, so I agreed.

*Pitocin started*

So, when I got there, OR  
They started the pitocin.  
I got the epidural.

*I should have asked more questions/Regret*

The epidural was not pleasant at all EV  
A resident, I think [did it], OR  
Now that I look back  
I would have asked more questions. EV

*The epidural was stronger on one side*

But, a resident did the epidural OR  
And it started, started to work.  
I could tell it was working,  
But then one side was obviously more, EV  
Was stronger on one side than the other.

*Nervous*

So that started making me nervous EV  
To begin with  
Then things just started progressing. OR  
I started to get more contractions.  
I wasn't in any real, real pain at all  
because of the epidural. EV



*Nurses checked my labor progress*

It went on for a while

The doctor would come in.

Well, the doctor didn't come in for a while.

The nurses would come in

And check my progress.

OR  
EV

*Time to push*

When I finally got to ten centimeters

He [the doctor] said, it was time to push.

CO

*It was busy/ interruptions/distractions*

And by that time,

They had told me that all the rooms were full.

It, it was completely like the busiest

that they've had it in like years.

I think they said there were 25 people in labor

At the same time.

CO

*Attempts to focus*

So, I was like,

"Okay. Well, I don't, you know, I'm here havin' a baby,

So, I'm just gonna focus on me right now."

But it was like people in the lobby,

Starting to push

And all kinds of stuff.

It was crazy.

OR

*Nervous*

So, apparently,

I don't know if it was a full moon or what,

But it was really, really, really busy,

So you could hear people, outside

And I think that started to make me nervous too.

EV

*Where's my doctor?*

I was like,

"Where's my doctor?"

"Is he going to have time for me?"

So, it was time to push

And it was just my husband and I in the room.

CA

*Mom and sister wait with camera to hear cry*

My mom and sister were outside the room.

I told them to stay there with the video camera

So they could hear the crying and everything.

OR

*I pushed for hours/ it seemed like forever*

And it seemed like I pushed for five hours.  
 It seemed like it took forever. EV  
 The doctor came in once to check my progress.  
 And it was coming along.

*Baby turned wrong*  
 I think the baby was turned a little wrong. CA  
 But he said just to keep pushing with my contractions.  
 So, I kept pushing  
 And it was almost three hours later  
 That finally he [the doctor] came in  
 And it was time to be delivered.

*Baby stuck/ cord around legs*  
 Jay was delivered  
 And he was coming out. CA  
 He was stuck.  
 They [nurses] said,  
 his umbilical cord was wrapped around his legs

*This is where his birth Injury took place*  
 So, I don't know if he just couldn't come out  
 Or if, this is where it starts to get weird,  
 Like they don't know what happened,  
 But this is where his injury took place. EV

*Forceps/Episiotomy*  
 They used forceps to get him out. CA  
 And he came out fine.  
 I had an episiotomy  
 And he came out fine. EV

*No immediate cry*  
 I didn't hear him cry right away CA  
 Which automatically scared me  
 And I did see him  
 But they rushed him to the... OR  
 They took him to the room next to my room.

*Everything was fine*  
 And I did see him.  
 He was really purple CA  
 And I heard him cry  
 And everything was fine. EV  
 They said everything was okay.

*I was happy/everything seemed fine*  
 So, I was happy EV

And they bundled him, cleaned him up,  
 Bundled him up and brought him back to me.  
 And everything seemed fine.

OR

EV

*I gave him a bottle*  
 They sewed me up.  
 I didn't breast feed.  
 I didn't breast feed.  
 I'd chosen that before I got there  
 So they gave me a bottle to feed him.

OR

*He was purple/pale but they said that was normal*  
 So, I got to feed him  
 And he seemed fine.  
 He was very purple to me.  
 Just pale looking  
 And, but they said that that was normal.  
 He was fine.

EV

*Spending time with him*  
 So, I got to spend some time with him  
 And held him  
 And took pictures  
 And all that.  
 The family got to see him.

OR

*Baby went to regular nursery*  
 And they took him to the nursery  
 The regular nursery.  
 He was fine.  
 So, I was like, "Okay.  
 Well, they'll bring him to me,  
 once I get to the recovery room.  
 And we can spend time with him there  
 And he can sleep in my room  
 And all that stuff.

RE

Birth story ends

EV

*I thought everything was fine*  
 So, I thought everything was fine.  
 And we waited in the labor room for hours  
 Just tryin' to get me a room to go to  
 Because it was so busy.

EV

OR

*Busy doctor*  
 I think my doctor probably delivered several,  
 A lady came in after me  
 And he delivered her before me.  
 Like, it was, it was crazy.

OR

*Neglected to be checked on*  
 I think that was part of ...  
 I still, we still don't know what happened  
 But, I think that was part of it  
 I think maybe I was not forgotten about  
 But kind of neglected to be checked on.  
 And I think he [the baby] just stayed down there too long.  
 Anyway, so everything was fine.

CO

**Elizabeth mother of Owen  
 Disenchantment/NICU**

***[later that evening]***

*Baby transferred to NICU*  
 I think it was about 3:00 am,  
 A nurse came in from the newborn nursery  
 And said that they didn't like the way that he was breathing.  
 And that they were going to transfer him to the NICU  
 Just to keep a closer eye on him.

OR

CA

OR

*They didn't make it sound serious*  
 I said, okay.  
 They didn't make it sound like it was anything serious.  
 That this was normal.  
 He could have just aspirated something.  
 And that he should be fine,  
 They just wanna keep an eye on him.

EV

*Called my parents*  
 So, I didn't think it was a big deal.  
 I tried to wait until 5:00am to call my parents  
 And tell 'em that they transferred him to the NICU.  
 And they freaked out, flew up to the hospital  
 and because my mom was an NICU nurse.

OR

*Wheeled to NICU*  
 So, about the time they got there  
 I think it was between the hours that you could visit.  
 So as soon as I could, I got in the wheelchair  
 And my husband pushed me to down to the NICU.

OR

*Seizures*  
 And by that time,  
 they told me that they had seen him seizing,  
 that he was having seizures.

CA

And when I got there,  
I saw him have a seizure  
And it was, I knew this was gonna happen,

*Witnessed seizure*

It was like the most awful thing that I've ever seen.  
And he was in one of the nursery beds  
And he got really stiff  
And one of his arms stretched across his chest  
And he turned his head and stared off for a minute  
And was really red.

EV  
OR

*MRI of brain*

I was like, "Oh my gosh!"  
Like this is a seizure  
And he's been doin' this a couple of times.  
And we sent him to get a MRI.  
He needs to have his brain looked at,  
So I was freaking out.  
And I couldn't think straight

CA  
EV

*Questions of why?*

And my husband was asking, "Why is this happening?"  
Everything went totally normal.  
We're like, "Why? What happened?"  
And they explained, they don't know why it was happening.  
That the MRI will show what is happening.

OR

*Waiting*

So he had the MRI  
And we waited back in the recovery room for the results.  
For him to come back.  
And they called and said that he was back,  
That we could come see him  
And that one of the doctors wanted to come talk to us.

OR

*Why does he need a neurosurgeon?*

So, we said, "Okay"  
So, we got to the door and the doctor met us at the door  
And he said, "I'm Dr. Allen, the neurosurgeon."  
And I just totally freaked out.  
I was like, "Neurosurgeon?"  
Why in the world is he going to need a neurosurgeon?"

OR

*Receiving MRI results*

And I just couldn't  
From that point on,

I was just hysterical  
 And he took us to the little room [radiology room]  
 To show us the MRI

EV  
 OR

*Conversation with neurosurgeon*

He was very calm,  
 He made me feel better  
 because he knew what he had to do,  
 He explained, "we don't know what happened,  
 but this is what is wrong with his brain.  
 We're gonna fix it.  
 This is what we are gonna do.  
 Just very matter-of-fact.  
 This is the steps that we'll take  
 And so I knew that he knew what he was doing.  
 So, I totally trusted him.

EV

EV

*Subdural hematoma*

But he showed us the MRI  
 And he had a subdural hematoma on his brain.  
 Not on his brain, but between his brain and skull.  
 And we asked several times,  
 "What caused this?"

CA

*I should have had a C-section*

No one, will tell us  
 and I think it was because  
 it was the fault of one of the doctors  
 either using the forceps  
 or him [the baby] being down there too long.  
 I think I should have had a C-section  
 Is what I, in my heart believe.

EV

EV

*Force of labor is the cause*

But he [the neurosurgeon] said,  
 the force of the labor,  
 the traumatic labor  
 caused the bruising on his brain.

CA

*Increase ICP/ surgery/external drain*

And that the pressure had to be relieved  
 And to relieve that pressure  
 Of spinal fluid building up  
 They would have to put a drain in,  
 An external drain.

CA

*I can't believe this is happening*

And so all of this was just...

I wasn't comprehending.

EV

I was,

But I was like,

"I can't believe this is happening

to the most normal person in the world."

*Life-Threatening condition*

So, I tried to wrap my head around that

OR

And say, "Okay. Well, do it now because

if it gets, if the pressure gets any higher,

He, he wouldn't have made it."

CA

So, he [the neurosurgeon] said,

"We're gonna take him into surgery today."

RE

In my interview with [not in this excerpt], Elizabeth, she said that she watched "A Baby Story" and "Bringing Home Baby" on television and attended birthing classes to prepare for childbirth. She noted that the televised stories and the birthing classes only prepared mothers for the ideal birth experience, of how things happen if they all go according to plans. However, when birthing plans go awry, mother's like Elizabeth are left feeling ill prepared for the realities of life.

Elizabeth also described, receiving an invitation to the childbirth class reunion. This invitation was sent out to all mothers who attended the birthing class, inviting them to come back to tell others about their birth story. But Elizabeth felt that nobody would want to hear her story, so she didn't attend the reunion. She also explained that mothers were invited to bring their newborn baby with them to the reunion and she did not have a baby to show yet. Jay was still in the hospital. Elizabeth disregarded her birthing class reunion invitation and continued her daily visits to the NICU to spend time with Jay. Elizabeth's story helped to illustrate feelings of isolation that many NICU mother's feel when their plans for pregnancy, birth and baby are disrupted or go awry.

In my interview with Elizabeth, she said that she did not want to be the “Debbie Downer”. Elizabeth said, now “when I hear people are pregnant, I want to tell them to be sure you ask questions.” “Ask questions, if something doesn’t seem right or if you haven’t seen the doctor, make sure you ask for him.” Now, I’m like the “Debbie Downer”. Elizabeth wishes now that she had asked more questions. She said she tells other mothers now that “Even if it seems stupid to you, ask!” “Ask. Don’t be afraid to ask.”

Elizabeth explained that this was her first pregnancy; she had no idea what to expect. She assumed that the birthing pain was normal. But now she said that she would be asking, “Should I be feeling this?” “Why am I feeling this?” But, at the time, Elizabeth did not know to ask those things. Instead Elizabeth was being agreeable, following the instructions given to her by the healthcare team.

Watson (1985) identified the acceptance and promotion of expressions of positive and negative feelings as one of the major carative factors and part of nursing’s core. Therefore it is important for the nurse to be attentive to people’s feelings in the maintenance and promotion of health and to people’s response to illness (p. 48). According to Watson (1985), the quality of one’s relationship with another person is the most significant element in determining helping effectiveness. Unfortunately, Elizabeth’s labor and delivery nurse did not establish such a relationship with her. In my interview’s with Elizabeth, she expressed that she felt ignored, neglected and silenced. Her doctor and nurse talked to each other but they did not include her in their conversations. She only



understood what was happening with her and her baby by overhearing conversations taking place around her.

**Abbey, mother of Carlyn  
Disenchantment Story**

*Another World*

[N]ICU is a whole [a]nother world  
It's a whole different set of rules, regulations, expectations. AB

*Permission to Enter*

You pick up the phone  
on the outside of door  
To ask if you can come in  
Because you don't know  
if your child is out for testing OR  
Or the baby's with the doctor.  
So, you have to get permission CA  
to come through a set of doors.  
You get buzzed in.

*Hand Washing*

You wash your hands. OR  
You sanitize your hands.  
You scrub your nails.  
You go fingernails to elbows  
It's crazy  
You do your handwashing.

*ID Check Point*

Then you go down to the desk OR  
Where you give them your name again  
So that they can give you a numbered badge.  
So that they can be assured that you are on the list  
And that you are who you say you are.

*Visiting time clock is ticking while waiting*

Then, then you can finally go back  
to wherever your child is.  
And if somebody is with your child,  
then you still have to wait CA  
before you can actually get to your child

*Difference/Expectations gone awry*

It's, it's just not like that anywhere else.  
I mean, if, if your child's in the regular nursery  
You just pick up the phone and say,

"Can you bring me my baby?  
 They bring your baby to your room.  
 But it's totally different,  
 When your baby's in the [N]ICU  
 It's crazy.  
 I never, I never imagined that would happen to me.

RE

*I thought it was just me that was high risk*  
 I knew that I was a little high risk.  
 But I didn't think [it would effect the baby]  
 It was just me that was high risk.  
 I thought, "Yes, I run a little bit of high blood pressure"  
 I'm good.

CO

In a separate interview with Abbey, she elaborated on the NICU experience as not normal

*Baby Jail/Petting Zoo*

The hours for ICU  
 Kinda make you feel like  
 I, I hate to say it,  
 I mean it,  
 You, you have scheduled visitation.  
 So your child, is, is what?  
 In, in jail?  
 Or at a petting zoo?

AB

*Restrictions on mothering activities*

I mean,  
 There's only certain times that you can go.  
 You can go between this time and this time  
 But when you go, you're [limited as to what you can do]  
 I'm sure it's like that for different people on different levels  
 I mean every, every baby has a different situation  
 So there's different rules per se for everybody.

OR

*Mothering duties performed by healthcare providers*

Like, we'd go up there and I couldn't feed her.  
 For a while, I couldn't feed her.  
 Because, she was being tube fed  
 So, of course, you can't feed her  
 because she's being fed through a tube.  
 They said, she was burning too much blood sugar,  
 by sucking on a bottle.

CA

So, I couldn't feed her.  
 I couldn't hold her...

Because they put an IV through her umbilical cord...  
There are lots and lots of rules about the umbilical cord IV.

*Limitations on mothering*

So, I couldn't hold her.  
We couldn't bathe her.  
We couldn't feed her. CA  
I could come up.  
I could hold her hand.  
I could sit by her.  
I couldn't put clothes on her.

*Mittens and Fuzzy Socks*

I could put socks on her feet OR  
But that, that was basically it.  
And I could put little mittens on her hands.  
So, really for nine days, that's all she had [that was normal]  
Was the little mittens and the lil', little fuzzy socks. EV

In a third interview with Abbey, she went on to describe how being an NICU mother is different from normal mothers with normal children.

*Not like other mothers*

It's not like the other mothers, EV  
I mean,  
If you're a regular mom,  
The baby comes in your room in the morning, OR  
Doesn't leave unless there's shots or pictures or you get tired  
And you ask them to take your baby back to the nursery.

*Taken-for-granted assumptions*

When you have a baby in [N]ICU,  
It's like, okay...  
The normal mothers with the normal child, CA  
It's like, okay, well,  
this is just everyday life.  
This is how it happens.  
This is everyday.

*My child's down at the Jail house*

And then for your child in ICU,  
It's like, okay, my child's in ICU.  
That's like tellin' 'em my child's down at the jail house EV  
Because I can go visit my child  
between 8:00 and 10:00 and then  
between 12:00 to 2:00 and then  
Between 4:00 to 8:00

*It's a crazy schedule*

You're being told when you can see your child.  
 [Your entering through] a locked door.  
 You pick up the phone.  
 You have to show your ID bracelet that's on your arm.

CA

*Important rules that make mothering awkward*

It was nuts.  
 It's like, I mean, you're happy  
 That they do that because that way  
 It keeps security pretty tight  
 Because anybody could just walk off  
 with your kid [without security].

EV

Abbey, mother of Carlyn, talks about the NICU as a "another world": a world where a mother goes through a process (permission to enter, hand washing, ID check points) numerous times each day to visit her baby. She also noted that visiting hours are limited and as she waits for entry, the visiting time clock is ticking away. Daily visits to the NICU reminded Abbey of her difference in the world, a world that regular or *normal* mothers with their *normal* babies do not have to experience or even know exist.

Abbey thought that she was a little "high risk" due to her high blood pressure, but she thought that it was her problem. She did not understand that her high blood pressure could have effects on the baby like intrauterine growth retardation and hypoglycemia, contributing to an NICU admission. Abbey never imagined that this would happen to her and her baby. She described visits to the NICU as visits to "baby jail" or a "petting zoo," because it involved scheduled visitation and ID check points like a jail or zoo; normal mothering activities were restricted to professional care providers, making it feel like a petting zoo. The only thing that made the experience feel normal, were the mittens and fuzzy socks that she dressed Carlyn in.

Abbey's experience was not like that of "normal mothers" with their taken-for-granted normal activities of mothering, such as having their newborn infant stay with them in their room in the post-partum period for feeding, holding, bathing, and bonding. Her experience was one of being "different" and alienated from the idealized mother experience; her baby had serious medical concerns (hypoglycemia) that required the intervention of healthcare professionals and therefore she was resigned to the NICU (baby jail), a place of confinement for babies who have been sentenced with a medical condition or illness or who are unable to gain release while awaiting diagnosis and cure. In this world, Abbey's expectations had gone awry and the endings that she had imagined for herself and her newborn baby were no longer clear.

Abbey expressed her understanding of the NICU rules and regulations, and the NICU entry process as a way to provide for and maintain the baby's safety and security. However, the rules, regulations and expectations of the NICU did not match the hopes, plans and dreams that Abbey had for her expected, ideal birth experience and baby.

Disenchantment stories were found to be stories about lost hopes, wishes and dreams. They were stories that illustrated the mothers' attempts to make some sort of sense of things, to search for significance in the events and to reveal their meaning. When connections could not be found, mothers began to understand life as vulnerable and unpredictable. With time mothers began to believe that some things are unknowable and they began to reconcile and adjust to their new life and role as the mother of an infant in the NICU.

As the participant mothers began to come to grips with life's uncertainties and vulnerabilities, they also began to accept what life had thrown at them. Mothers not only saw the worst in their experiences, but they also found joy, exuberance and fulfillment in their experience. With a slow and gradual acceptance, mothers began to tell a new type of story. I have identified the third story type as *re-enchantment* stories. These narratives include stories of love and hope for the future, a future not negated by threat and loss. I will discuss this story type and provide examples from participant interviews in the section that follows.

### *Re-enchantment*

In narratives of *re-enchantment*, the mothers' life story must be reconstructed to fit a set of life situations different from those originally, idealized expectations. Mothers' often told about their attempts to reorganize the future or return to a more normal life with their baby. They described their efforts to create normalcy in the chaos of the NICU by being involved with their baby's care. They began preparing a place in their life story for an altered set of hopes and dreams. The mothers identified with different ideas about life. With time, they began to incorporate those new possibilities into their identities as mothers, looking to the future with new ideals, hopes and dreams. They embarked on a journey of acquainting themselves with a different baby and life than was previously imagined. They created memorable moments and found new ways to celebrate each new achievement and milestone.

In the section that follows, Raelee tells a story of trying to create some sense of normalcy for herself and Owen with the *Easter outfit story*. First, to set

the scene, Owen was born on January 2, 2008. By Easter Sunday, both Owen and Raelee had experienced eighty-one days of highs and lows in the NICU. Owen had been through surgery for a bowel perforation, had gone through laser eye surgery for retinopathy of prematurity; had finally weaned from his ventilator to nasal continuous positive airway pressure (NCPAP) and then to nasal oxygen cannula. He had moved to level II (a less critical status, but continued to require continuous monitoring) where he was growing and learning how to eat in preparation for discharge. Raelee felt that she and Owen had been on a high for a while. She was excited about Owen's progress but remained somewhat skeptical about his readiness for discharge in the next month or two.

One week before Easter Sunday, Raelee had purchased an Easter outfit for Owen. She had thought that since Owen was improving and was now on the nasal oxygen cannula that she would be able to dress Owen for a special Easter celebration. But a few days after her purchase, Owen had a bad day; he was having increased difficulty breathing and began requiring more respiratory support from NCPAP. Raelee, became extremely upset when she came to visit that morning and found out that Owen's condition was worsening. She had been experiencing a high for a while, had anticipated things moving forward in the direction of discharge but suddenly she was experiencing another downward spiral. That day, Raelee, left the NICU. She said, "I am done. I can't [do this] because he can't do it and I'm not doing him any good being here because all I do it cry." The whole time Raelee was in the NICU that morning Owen cried. Raelee felt like Owen hated the NCPAP prongs in his nose and there was nothing she could do to help him. So she took a break away from the NICU and

got some rest at her sister's house. She said, "I cannot go back and see him like that. I'm sorry. I'm through for the day."

But the next day, Raelee returned; she decided that her "pity party" could not go on. She had to be there for Owen. Raelee returned everyday that week, although she was admittedly depressed. She sat at Owen's bedside, waiting for him to improve as Easter Sunday was drawing near.

**Raelee, mother of Owen  
Re-enchantment Story**

*The Easter Outfit*

The one thing that I wanted to do  
to make all this feel kinda normal  
is for him to be able to wear a little Easter outfit AB

*Some people thought it was stupid/For me it meant he's fine*  
And to some people that was the stupidest thing CA  
To worry about a Easter outfit  
But to me it was everything  
Because it meant, he's fine.

*On nasal cannula/Can be dressed*  
We can move him around  
We can get him dressed OR  
He'll be back on his nasal cannula  
Everything's fine

*Most important*  
That was the most important thing to me EV  
The most important thing to a normal parent  
Is not if their child is going to wear an Easter outfit  
I understand that  
But to me, it was.

*There are more important things to worry about/Resistance*  
That was the most important thing.  
And I remember somebody telling me CA  
That I had more important things to worry about  
Than him having an Easter outfit on  
And I just remember thinking,  
"No, I don't. I'm sorry, I do not.  
This is important right now"



*Easter Sunday*

And so Easter Sunday  
 I came back [to the NICU]  
 I had gone home to go to church  
 And came back expecting to see him there on NCPAP  
 And what do you know?  
 He's on nasal cannula again.

OR

*That's all I wanted*

And I just remember crying and thinking  
 All this time, that's all I wanted.  
 I wanted him to wear an Easter outfit  
 And so I was like, "He's not gonna get to wear it today  
 But tomorrow he is putting on a Easter outfit."

EV

*Easter Monday/ Pictures*

And so the first thing I did on Monday morning  
 Is put on his little Easter suit  
 And do pictures

OR

*He was normal*

And it was great  
 It was wonderful because I,  
 He was normal then  
 It was all normal

EV

*The need for normalcy*

[I got to] get up and put my child on his Easter clothes  
 To go to church Easter Sunday  
 And that was what I needed  
 Some normalcy at the time.

CO

**Elizabeth, mother of Jay  
 Re-enchantment Story**

*Normal Clothes*

I remember the first time  
 When he had normal clothes on  
 And I thought "Oh, you put normal clothes on him"  
 I thought that was the most wonderful thing ever

AB

EV

*Covering stuff/wires/tubes*

When he could finally have clothes on  
 Over all of this stuff [covering the wires and tubes]  
 I took pictures of him in his first outfit  
 I thought it was great.

EV

*He couldn't have a normal bath*  
 He couldn't have a normal bath CA  
 I thought it was cool how they EV  
 Would give him a sponge bath OR  
 With a little blue tub  
 Just wipe him down

*Personalizing his space/Picture of Grace[the family dog]*  
 And they let us put little toys in there OR  
 And I taped a picture of Grace to his bed  
 I thought that was nice EV  
 I didn't think they'd let us do anything  
 To personalize his space.  
 But we did that RE

Later, after Jay had VP shunt placement, he was doing well and the surgeon released him home. Elizabeth said,

*We treated him like any other baby*  
 I went about my business AB  
 like I think I would with any other baby  
 we went to Target OR  
 we did our thing  
 we took rides in the car when he'd cry

*I don't treat him any different/we are careful*  
 I have not treated him any different CA  
 I watch to make sure he doesn't CA  
 Lay on hard things that could hurt his head

When we put a paci in at night CO  
 When he falls asleep  
 We always go in  
 And make sure we take it out  
 Because we're so afraid that he'll lay on it wrong. EV

**Suzie, mother of Terrell  
 Re-enchantment Story**

*Nurse explained*  
 She [the nurse] put her hand on my back and said, AB  
 "You've got a beautiful little boy there  
 and he is strong."  
 She explained his equipment  
 and how it would help him to get better.

*Encouragement/Reassurance helped*

That kind of got my hopes up,  
I got excited,  
just that little bit of encouragement helped.  
Because she was working with him,  
it helped me a lot, to have reassurance  
from some...from a medical person.

EV

*Nurse helped when you felt upset*  
There was a time,  
some of the nurses they cut up a lot.  
It helps when they make jokes  
or are laughing and smiling.

EV

*When you can't bring baby home/Can't do certain things*  
It helps you because you are upset  
because you can't bring your baby home  
and you can't do certain things.  
It's hard  
but then when the nurses come in there  
and they cheer you up, it helps.

CA

CA

*The nurses showed me how to care for him*  
After you've been there a little while,  
the nurses would show me  
how to care for him.  
They supervised me the first time  
and after they saw what I was doing  
they pretty much let me go with it.  
They would pretty much give me report  
and then I'd take over from there.  
They would just make sure  
that I didn't have any questions.

CA

*This is my time/ I got to do more for him*  
Then, I got to do a lot more for him  
I got to take his temperature  
I got to give him a bath  
I would change his diaper  
and feed him.  
I felt like, "Okay.  
This will work,  
this is my time."

OR

EV  
RE

In another interview, Suzie described her experience as life changing

*I get a whole new life*  
The experience is life changing  
and very meaningful.

I still get a whole new life  
and the way I do things,  
the way I act,  
and my behavior  
in a lot of different ways,  
how I treat people,

AB

*refers to her life-threatening event*  
because you never know  
when things will happen  
or something serious  
or bad is gonna happen  
or when they're gonna leave you  
or when you're gonna be here forever.

CA

*I look at it as a blessing/It has taught me a lot*  
This experience has taught me  
to be thankful for what I have.  
At first I was real scared  
about the pregnancy,  
but now I look at it as a blessing.

EV

*Demonstrates faith and hope*  
God put him here for some reason  
and I'm here to take care of him  
and obviously he thinks I could do it.  
So I hope for the best.

OR

*I cherish him more because I almost lost him*  
I am thankful that he is healthy now.  
There's just different things I look at,  
To see him smile.  
It touches me a little deeper  
than it would if I had not experienced that.  
I cherish him a lot more  
than I would during a regular pregnancy  
because I almost lost him.

EV

CA

#### *Promises*

I made promises to Terrell,  
that I would always be there for him  
and that I would do the best I can raising him,  
and I would do the best I can  
to give him everything  
and anything he needs.

*Pictures show how far we have come*  
I kept pictures

so that I could look back  
and say, he came from that  
to be a big ol' fourteen pound whopper.  
He's come a long way.

EV

*Family support*

The support from my family helped out a lot.  
My family taught me  
about taking on the responsibility  
caring for a baby  
and if I didn't have that experience,  
I wouldn't know where I would be standing right now.  
If not for my family,  
I'd be in a lot of trouble.

EV

*Enjoy Life/Life is full of uncertainty*

This experience has taught me to enjoy life.  
To hold it very close to you.  
To love it with everything you have.  
To be sure that you let your family know  
how much they mean to you  
and not just let things go.  
Just enjoy the little aspects of life  
rather than worry about the big ones.

EV

*More Responsibility*

People say that the experience  
has made me more mature  
than other people my age.  
I believe having a baby,  
makes you a lot more mature  
and responsible.  
There is a lot of different things  
to be responsible for besides yourself.  
You've got to stay home  
and be a mom  
and take care of your baby.

CA

*I am a stronger person*

I'm going to work  
and coming home  
and raising my baby.  
It has helped me  
to be a stronger person than I was.

EV

*I almost lost my life/I almost lost my child*

The way I see it,  
this whole experience

EV

was just a lesson to me.  
 I have had to learn the hard way.  
 Life is not a game.  
 There are consequences.  
 And they're major.  
 I almost lost my life.  
 I almost lost my child.

*Regret/ making different choices*

CA

If I had made different choices  
 I wouldn't be having to go through this experience.  
 I could be in college  
 getting my nursing degree.

*Living with consequences*

CA

But I made my decisions  
 and I will live with the consequences  
 and I will share what I have learned  
 with Terrell someday.

*Values change*

EV

Life is not a joke.  
 You can have it today  
 and lose it tonight.  
 My values have changed.  
 I no longer come first.

*Baby comes first*

EV

Terrell comes first.  
 My priority is that he is taken care of.  
 I am concerned with making sure  
 that I am doing everything  
 I need to be doing for him.

*Value relationship with mother*

EV

I value my relationship  
 with my mother more now.  
 Our relationship has become  
 such a strong bond  
 that it's almost as strong  
 as mine and Terrell's.

*She was there for me*

EV

She was always making things a little easier for me.  
 Lightening the situation up,  
 Trying to coax me that it would be okay  
 For me, it was a relief  
 Because I had someone to lean on

Through that period of time.

I can't imagine not having my mom there  
 To lean on, to talk to about different things.  
 So there's really a relief to have somebody there.  
 I was just glad she was there for me.  
 When I took him [Terrell] home  
 It was like I just gave birth to him yesterday  
 It was our time.

*It's life changing.*

CO

If Tuesday was the last day that I lived,  
 I wouldn't have been happy with myself.  
 There was distance between me and my family

Suzie, described her near death experience and her NICU experience as life changing. The experience had transformed her values and her taken-for-granted assumptions about life. She has learned to cherish the little things like a smile from her baby and important relationships with her family. Suzie acknowledged that she got a second chance at life. She expressed it this way: "When I took him [Terrell] home [after being in the NICU for 29 days], it was like I had just given birth to him yesterday, it was our time."

Suzie ends her re-enchantment narrative with the mention of rebirth; it seems that she sees her disenchantment story as a turning point. She is now re-encharnted by the possibility of "second chances". She looks forward to establishing more meaningful relationships with her family and to diminish the distance that once separated them. Suzie got second chances to provide for and care for her baby. She got second chances at a life that had previously been taken-for-granted. Suzie recognized how close she came to her baby's death and looks to the future with new ideas, hopes and dreams.

**Abbey, mother of Carlyn  
Story of Re-enchantment**

Abbey described a story of re-enchantment when she finally came to understand Carlyn's condition of hypoglycemia in a way that made sense to her. She described that one physician, in particular, explained things in terms that she could understand. Abbey stated that, "the way he [the endocrinologist] explained it, it made a whole lot of sense. He [the endocrinologist] made it so that we understood exactly what we were dealing with."

*The medication*

[He put her on a medication]

AB

Diazoxide, an insulin inhibitor

And, he [the endocrinologist] explained it to us.

It slows down the amount of insulin that the pancreas makes.

*Explanation of Carlyn's condition*

When your diabetic,  
you have too much glucose  
and not enough insulin.

CA

Carlyn has the exact opposite.

*Stopping her pancreas from making too much insulin*

OR

She [Carlyn's] body, her pancreas  
is making too much insulin

So she can't keep enough glucose in her body.

The insulin is getting rid of it [the glucose]

So, they [the endocrinologist] wanted to  
stop her body from making [so much] insulin.

She didn't need it.

*Better glucoses/medication working/Prepared to go home*

EV

When the [insulin] inhibitor had actually done its job

And trained the pancreas to stop making

That much insulin

And she was having better blood [glucose] meter readings

He [the endocrinologist] came back [a few days later]

and said, okay, The medicine worked."

And we prepared to go home

*Teaching/ Discharge*

RE

Then [in preparation for discharge]



The hospital provided me with a blood sugar meter  
And I had to get a glucagon emergency kit.  
I had to speak with a diabetic [nurse] specialist [for training].  
I had to, I had to give a shot to a balloon or a little pillow looking thing.  
I had to learn how to measure out the medicine  
[and give it prior to discharge home].

Once Abbey completed medication administration and glucose monitor training, Carlyn was discharged home with her parents. After weeks of diazoxide treatment and glucose monitoring, Carlyn's glucose levels slowly increased and she was taken completely off her medication. The endocrinologist saw her for follow-up appointments two more times, but she never had to go back on the Diazoxide. At the time of our interview, Carlyn was a beautiful and interactive four month old.

Watson (1985) recognized that the promotion of interpersonal teaching-learning is an explicit way to reduce fear and anxiety when stress may be related to uncertainty and seriousness of a condition, procedure, operation or treatment. Abbey's re-enchantment story illustrates how the facilitation of learning improved this mother's perceptions about healthcare concerns for her baby.

### Summary

Three core narratives were identified in this study, enchantment, disenchantment and re-enchantment stories. I have attempted to illustrate each one here. In the next section, I will continue the analysis by looking at interview transcripts and participant journals for narrative features and transcendent themes.

## Narrative Features and Transcendent Themes

Thematic analysis of the participant mothers' responses were illustrated in narrative excerpts and yielded five narrative features with transcendent themes (see Table 5)

**Table 5**

### Narrative Features and Transcendent Themes

Narrative Features	Transcendent Themes
Causality and Contingency	<ul style="list-style-type: none"> <li>Tears in the fabric of daily life</li> <li>Mourning a life as it was imagined</li> <li>Questions of Why?</li> <li>Search for Answers</li> </ul>
Temporality	<ul style="list-style-type: none"> <li>Rollercoaster</li> <li>Time Waiting</li> <li>Baby jail or Petting zoo?</li> <li>Tailored Care</li> <li>Assembly Line</li> <li>Desire for Normality</li> <li>Burden of Depression</li> <li>Prior Experience with Illness and Death</li> </ul>

Table 5 (Continued).

Narrative Features	Transcendent Themes
Singularity	Tailored Care
	Assembly Line
	Desire for Normality
	Burden of Depression
Intersubjectivity	Encounters with Nurses
	Left Out of the Loop
	Earned Trust
	Butterflies and Curtains
	Protecting Family
	Family Support
Ethicality	Valued Responsiveness
	Vulnerable Aspects of Life
	Demonstrating Hope and Faith
	Desire to Help Others

The narrative feature of *Causality and Contingency* addressed the mothers' "urge to make sense of why things happened, it's longing to find or imagine connections among things, either through motive or cause" (Charon, p.48). This narrative feature was revealed in the mother's stories as mothers

described the following transcendent themes: Tears in the fabric of daily life, mourning a life as it was imagined, Questions, Search for answers.

### Tears in the Fabric of Daily Life

One participant's daily life was suddenly changed, while on vacation, when she noted vaginal bleeding, she described the incident,

*We were on vacation at the beach when it happened, so I was away from my doctor...I just didn't know what to expect—Raelee, mother of Owen, interview #1 p.1. Raelee also noted, Nobody goes into a pregnancy thinking, my baby's going to be premature. It was all so surreal to me, it wasn't happening. I just kept thinking, Wake up. You're in a dream. Wake up.—Raelee, mother of Owen, interview #1 p. 2.*

Another participant mother was at work and began to feel ill, she tested her blood pressure and it was elevated

*Everything went fine until May 11<sup>th</sup>, I was at work [as a certified nursing assistant in a nursing home] and I tested my blood pressure and it was elevated. They[coworker/nurses] told me to wait a little while and check it again, it was even higher. They sent me straight from work to the emergency room.—Suzie, mother of Terrell, interview #1 p. 1.*

In the excerpt that follows, Elizabeth's hopes, dreams and plans for her first birth and baby suddenly went awry when she experienced a long and difficult labor and delivery, and her baby received a birth injury.

*My pregnancy went totally normal. Everything was fine. I never felt better in my life. It was wonderful." Following a Pitocin induction and epidural, Elizabeth began to push with her contractions. She explained, "When I finally got to ten centimeters, he [the doctor] said, it was time to push...It seemed like I pushed for five hours. It seemed like it took forever. The doctor came in once to check my progress. And it was coming along. I think the baby was turned a little wrong. But he said just to keep pushing with my, when I felt the contractions. So I kept pushing and I want to say it was almost three hours later that he [the doctor] finally he came in and it was time to be delivered. Jay was delivered and he wasn't coming out. He was stuck. They said his umbilical cord was wrapped around his legs, so I don't know if he just couldn't come out, or if this, like they [healthcare providers] don't know what happened, but this is where his injury took place. They used the forceps to get him out and he came out fine. I had an episiotomy and he came out.—Elizabeth, mother of Jay, interview #1*

p. 1-3.

*The first week was the hardest because we didn't really know what was going on. We really never, planned for any of this to happen.*

—Elizabeth, interview #1, p. 7.

Another participant mother, Abbey began having low back pain while she was at her husband's business, she was 37 weeks along in her pregnancy and she thought she might be having contractions. She had her husband drive her to the emergency room to be checked. Abbey was later transferred to the obstetric unit. An ultrasound revealed that Abbey's baby was having drops in her heart rate with each contraction. Abbey was admitted to the obstetric unit for a 23 hour observation so that doctors could monitor her elevated blood pressure, the progress of her labor and her baby's response to labor. After it was observed that Abbey's labor was not progressing and the baby continued to have nonreassuring fetal heart tones, Abbey was officially admitted and scheduled to have a Cesarean section. Shortly after Carlyn was born, her blood sugar was tested and found to be low. She was then swaddled and placed in Abbey's arms for a bottle feeding. After the feeding, Carlyn's blood sugar was tested again but remained low and Carlyn was taken to the NICU for evaluation and treatment. In the excerpt that follows Abbey described that moment.

*The doctor noticed her shaking. And so they [nurses] did a blood sugar test on her. And the blood sugar would not read on the meter. And they took her from me... They told my husband a little bit of information, that she needed to go to the [N]ICU and that she was showing signs of hypoglycemia. And that they needed to get her on [IV] glucose. —Abbey, mother of Carlyn, interview #1, p. 4.*

Watson (1985) noted that "stress is magnified according to the person's instantaneous and intuitive appraisal of the interruption and whether the situation arouses an anticipation of harm, threat, or of challenge" (p. 82). For a mother

who's enchantment story has been interrupted by premature birth, infant and/or maternal illness or birth injury, the sudden disruption often creates stress, anxiety, and angst for the mother and requires coping. Watson (1985), suggests that provision for a supportive, protective, and/or corrective mental, physical, sociocultural and spiritual environment will help the nurse to care for the mother amid suffering and stress. According to Watson (1985), one of the most appropriate activities for the nurse related to stress and change is to obtain the patient's subjective, instantaneous, and intuitive appraisal of the stress producing event. Watson continues that intuitive, subjective appraisals can create distortions of the situation and inaccurate perceptions that lead to fear, anxiety, and anticipation of harm. Once the nurse has the subjective data, he or she can then help reduce the patient's anxiety by listening, accepting, and understanding. When the nurse understands the perceptions of the patient, he or she can then begin to provide cognitive information that can help to strengthen the person's coping mechanisms and provide situational support that can protect the patient from unnecessary stress (pp. 82-83).

#### *Mourning Life as it was Imagined*

*I think for about the first month of going to the NICU, I never once went in without crying or went out without crying.—Raelee, interview #1 p.2*

When Suzie was finally able to visit Terrell for the first time in the NICU, he was three days old. Suzie had been in ICU herself during that time, she described that first visit,

*After I touched him, I started crying, I was so scared he wasn't going to make it because he had all these tubes and IV's and everything hooked up to him.—Suzie, mother of Terrell, interview #1, p. 2.*

After Elizabeth witnessed her baby having a seizure she described the experience as follows,

*I saw him have a seizure and...it was the most awful thing that I've ever seen. And he got stiff and one arm just stretched across his chest, and he turned his head and stared off for a minute and was just red, I was like, Oh my gosh!—Elizabeth, interview #1, p. 4-5.*

Elizabeth described her reaction in the following ways, I was freaking out. I couldn't think straight. I was just hysterical.

*I wasn't comprehending. I was, but I was like, I can't believe this is happening to the most normal person in the world. Elizabeth, interview, #1, p. 5-6.*

Later, when Elizabeth was told that Jay would have to have a ventriculoperitoneal (VP) shunt, she said,

*His life flashed before my eyes, just having to be so careful with him and his dad plays soccer and I was thinking he won't be able to play soccer. We asked the neurosurgeon before he went into surgery all kinds of questions. Will he be able to learn okay in school? Will he learn and progress okay? And she said, "He should be fine. He can play sports. He can't be a football player. He can't be a boxer, obviously." She said, "He can play sports. He's just going to have to be extra careful, to watch his head.—Elizabeth,-interview #1, p. 10.*

Abby also shared a similar reaction to her baby, Carlyn requiring care in the NICU.

*I never, I never imagined that would happen to me. I knew that I was a little high risk [with hypertension]. But I didn't think it [my high blood pressure would effect the baby],I [thought] it was just me that was high risk.—Abbey, mother of Carlyn Transcript #1 p 17*

Watson (1985) noted that loss in its broadest sense exists when any aspect of one's self (whether tangible-concrete, intangible-abstract, real or imaginary) is no longer available to a person. Loss also exists when a valued object (including a person) is altered" (p. 269). Mother's in this study often

mourned the loss of a perfect or ideal pregnancy, birth experience and baby. Mother's also experienced loss of identity, including sense of self, Mother's also mourned her body's inability to carry a pregnancy to term and produce a healthy baby. Mother's in this study mourned lost opportunities to perform the "normal" activities of mothering, including, feeding, holding, bathing and bonding with her baby. Normal mothering activities were delayed in the NICU due to the baby's severity of illness and the need for complex medical care. Loss and the threat of loss was a constant source of stress for the NICU mother as she recognized her baby's fragile condition and as she witnessed the baby's moment-to-moment struggles for life and health.

#### *Questions of Why? Feelings of Guilt and Blame*

One participant mother had many questions when she was told that she needed to have an ultrasound to determine what was causing her baby's heart rate to fall with her contractions.

*Why? Why am I going for an ultrasound? Is there something wrong with the baby? Why? Why do I need to do this? Is there something wrong with the baby or is there something wrong with me? What is it? It's my first baby. What is it?---Abbey, mother of Carlyn, interview #2 p. 6.*

After Owens surgery for reanastomosis (reversal of his ostomy) he had to go on the high frequency oscillator ventilator. His mother was concerned because she had seen other baby's on it and it signaled to her that Owen was not doing well Raelee kept saying,

*Why is he on that? Why is he on that ventilator? What's the difference between Owen's [conventional] ventilator and the oscillator? Why does he need the more powerful ventilator? What is wrong with his little one? ---Raelee, interview #1p. 9.*



One participant explained that she felt responsible for her baby's premature delivery. She said that she had been given instructions from her obstetrician to go home on bed rest with bathroom privileges only but instead she prepared the baby's bed.

*I did something I wasn't supposed to, I put the crib together.—Suzie, mother of Terrell, interview #1 p. 1.*

Elizabeth searched for answers following her baby's birth injury and seizures by asking the following questions.

*Why is this, you know, why is this happening? Everything went totally normal. Why? What happened? Why in the world is he going to need a neurosurgeon? What, what caused this?—Elizabeth, Interview #1, p. 5*

When no answers were immediately available to her, she began to formulate her own perceptions of what must have happened.

*No one would tell us. I think it was because it was the fault of one of the doctors, either using the forceps or him, the baby being down there too long, and not, you know, I think, I should have had a C-section is what I, in my heart believe. But he [the neurosurgeon] said the force of the labor, the traumatic labor caused the, the bruising on his brain. And that the pressure had to be relieved and to relieve that pressure of the spinal fluid building up, they would have to put a drain in, an external drain. —Elizabeth, interview #1, p. 5.*

Elizabeth explained,

*I took care of myself, I didn't drink or smoke anyway, but I didn't do anything I wasn't supposed to do. I exercised. I wanted a healthy baby and I knew I was healthy. Nothing should have been wrong. My ultrasounds were fine. They never saw anything wrong. His [Jay's] heartbeat was always fine. I never had any reason for something to be wrong...The only thing afterwards, I thought, Why didn't I ask more questions? —Elizabeth, interview #1, p. 25.*

When Elizabeth found out that Jay would need a permanent drain (VP shunt), she had additional questions for the neurosurgeon,

*Will he be able to learn normally? Will his motor functions be alright? Will he be able to see? Will he be able to play sports? Will he be in a normal learning class?" All of that stuff runs through your head. We asked him a lot of things and he seemed to think that he'll have a normal life, be able to play sports, he can't be a boxer or a football player anything like that, but I'm alright with that. So, he'll be as normal as they come. We've just got to be careful.—Elizabeth, interview #3, p 9.*

### *Searching for Answers*

Mothers often searched for answers independently from the information given to them by healthcare providers. Their search for understanding and answers took many forms. In the section that follows, I provide examples from interview excerpts regarding mothers' knowledge seeking behaviors.

*You read about some of this stuff, cause you read books...but you still don't get all the information that you really need and babies don't come with books.—Abbey, mother of Carlyn, interview #2, p. 6*

In the beginning one participant noted that she had not done enough reading because it was scary and painful. It was too hard to think about what could happen.

*I hadn't really read as much as I probably needed to just because I couldn't [it was too scary, too painful]. After a while, I read like every day something different so I would know if it was going on with him—Raelee, mother of Owen, interview #1, p. 6.*

After Owen had surgery for bowel obstruction and meconium ileus the surgeon told Raelee that Owen might have Cystic Fibrosis (CF),

*I'd started researching CF, and then I knew that I had two things to worry about: him having lung damage and him having CF, you know, that was the two things I concentrated on. I worried myself sick over it. Raelee, interview #1, p. 9.*

Two weeks after surgery, the CF tests came back negative. But Owen's surgeon was convinced he still had it. She [the surgeon] thought, they [the lab] didn't test enough mutations. She [surgeon] sent more test.

*So, it was like a month that I worried my kid had CF because they were just convinced, if he had this [bowel obstruction/meconium ileus], then he had that [CF]. I mean, it was textbook and I guess he just is not text book. I guess he's a little different. —Raelee, interview #1 p. 10.*

The repeat test later came back negative for CF.

Elizabeth described the approach that she and her husband used to obtain information on her Jay's diagnosis of subdural hematoma,

*We did a lot of googling that night. About the brain, parts of the brain, the ventricle, we had to learn what all that was, the normal flow of the spinal fluid. We had to learn all these terms, we sounded pretty smart when we were talking. For example, we would say, his ventricle won't circulate the cerebrospinal fluid, and now he has acquired hydrocephalus. Everybody was like, What? What? Yeah. That's what we have to deal with. So, we looked up all kinds of stuff just to know, to try to learn more about what was happening. We googled the doctor [the neurosurgeon] and found out that he was the top in his field. Once we saw that too, I guess it eased out mind that we had the best neurosurgeon there is. We thought, Oh. Thank goodness! He's got the best. We only wanted the best course. ---Elizabeth, interview #2 p. 28.*

In analyzing the accounts, it was clear that following the infant's admission to the NICU all participant mothers experienced abrupt and profound disconnections from their taken-for-granted lives and they attempted to make sense of their experience.

The narrative feature of temporality was identified in participant mothers' stories and this narrative feature addressed how the mothers articulated the experience of time. Charon (2006) noted that this narrative feature can teach us where participants come from and where they are going, allowing us to understand the meaning of their lives. Transcendent themes with features of temporality identified in mothers' narratives include: Rollercoaster, Waiting, Baby jail or petting zoo?

### *Rollercoaster*

For mothers in this study, time was noted to speed up with a sense of urgency at times and drag on at other times. Time was reversed with decline and moved forward with progress. The pace of movement was always in flux. There was always something just around the bend. There was always something to worry about. In the section that follows, participant mothers provide examples of NICU time.

*It was always [something], I mean everyday you're there, there's something always hanging over your head. You get past one thing, then you gotta go past another. And it starts off major and then it gets to something not as major. I mean, [with Owen], the surgery was a big thing, then we concentrated on the ventilator. Once we got him off the ventilator, it was getting rid of the TPN... You are always trying to get to the next point. And there's always something hanging over your head. So it's never, never like everything's fine, except the last day... But while your there, there's always something that you have to focus on, worry about, and pray that he gets over. All the time. ---Raelee, interview #2, p. 60.*

*It's an emotional roller coaster. You go up and down. One day it's great. Everything is lookin' up. Everything, you think, Oh good! If my baby stays doing good for another 24 hours, then we get to go home. But somewhere in that 24 hours, somebody reaches down and smooshes you like a bug. And says, Oop! Not today. And then all of the sudden you're back at stage one again and you're like, okay. Alright. 24 hours. We have to be good for 24 hours.---Abbey, mother of Carlyn Transcript of Interview #1, p. 14.*

Abby, elaborated further on the roller coaster experience stating in interview #3 that,

*you wake up in the morning, you're happy, it's another day. You get up, you go see your baby. And then all of a sudden you're back down on the other side again. It's crazy.---Abbey, interview #3.*

*A lot happened in a little bit of time. And you think having a child in ICU, she was only there for 12 days. I felt like she was there for 12 months. Those 12 days were the longest 12 days of my life.---Abbey, mother of Carlyn Transcript #1 p. 18*

Raelee's narrative was full of ups and downs as her premature baby, Owen, lived through chronic lung disease (CLD), bowel obstruction/ meconium ileus, the possibility of CF, a second surgery for reanastomosis, steroid treatment and extubation from the ventilatory, and just when she thought things were looking up Raelee found out that Owen had Retinopathy Of Prematurity (ROP) a disease of prematurity that in its serious form causes blindness. In the passage that follows Raelee begs that Owen's sight be spared.

*You know it was like a up/down, up/down all the time. You're never up and stay up until you walk out the door. Never. You're always up and down, up and down. I remember thinking, " Yeah! He's back on nasal cannula. Everything's great. And then they came in to do his eye exam again, third eye exam, and they're like, "He went from no ROP at all to stage three." Well I had already researched ROP, because that's one of the things, [It, the subject of ROP] is a normal thing to talk about [in the NICU], that there is ROP. So, I knew when he [the pediatric ophthalmologist] said, "He's already at stage three" it was serious. I remember praying, you know, Lord, you have gotten [him] through so much and he needs to see what the world is all about. Don't take his sight. PLEASE. You know. I can handle us coming home with oxygen, I could handle him having to have an ostomy bag. I want my child to see.*  
 ---Raelee, interview #1, p. 12.

Owen had laser surgery for his ROP two days later and in his follow up eye exams the ROP had regressed (a good sign). But that would not be the end of Raelee and Owen's rollercoaster ride.

Owen had to be intubated and given sedation for his ROP surgery. That meant that he was back on the ventilator and with his CLD, it was anticipated that getting him off the ventilatory again would be difficult. Upon hearing the news, Raelee just cried and cried. She told her mother, "I want my baby to see but I don't want him on the ventilator." Raelee was worried that if Owen had difficulty this time getting off the ventilatory the next step would be a tracheostomy. But

surprisingly, later that day, Owen was extubated from the ventilator and was placed back on nasal cannula. Raelee said,

*It was like my up/down again, you know, I was finally up again. Finally, Owen was back on nasal cannula, his bowels were back together, he was using the bathroom. We had to go through some ups and downs getting him to eat. But I was just on a high for a while and about a week before Easter after I'd gotten him a cute little Easter outfit...He had a real bad day. (see previous section, setting the scene for Raelee's Re-enchantment Story/Easter outfit story).*

In a follow up interview Raelee, summed up the experience,

*The NICU is one big rollercoaster. That is the best way to describe it...You're gonna have days where you're so excited and the next day, it might all come crashing down. And that is. That is the best term. It is a roller coaster. Up and down and turning all around. It is. Nothing, there's nothing else to describe it. I mean, there's nothing like it.—Raelee, interview #2, p. 67*

Elizabeth also described the ups and downs of her experience. Following the placement of Jay's ventriculostomy (external drain), things were looking up for Elizabeth and her family. The drain was doing its job and relieving the intracranial pressure and Jay was showing signs of improvement. One day, the neurosurgeon decided that the pressure had improved enough that the drain could be removed.

*So, we thought that was it. You know, after that we get to go home. He'll be normal. It'll be fine. And so he stayed there a couple more days just for observation. And then one night after his drain was removed, one of the nurses saw that the suture was leaking and that the spinal fluid was following that track of least resistance in trying to get out of the hole instead of down the spine where it's suppose to reabsorb. So, they didn't like that. And the Dr. put another stitch in just to see if maybe it wasn't tight enough but that didn't work. And so, the doctor decided that he would need a ventriculoperitoneal (VP) shunt put in. So, that was another [brain] surgery altogether and that one was, I think harder than the first one because I thought after that [first surgery] that was it. We were done. You know, that we could leave and everything would be fine. And this [VPshunt] was permanent. And that scared me, when the doctor told me that may be one day it could come out but to think of it as a permanent thing.—Elizabeth, interview #1, p. 10.*

*In the next example, Suzie, mother of Terrell, described a time when her hopes for discharge were suddenly dashed. Terrell had been moved to level II. He was off oxygen, he was in a crib and he was learning how to feed in preparation for discharge home in a matter of days. But things suddenly changed when Terrell had a choking episode, and nurses and doctors suspected that he had aspirated formula into his lungs. Suzie recalled,*

*They called me when they figured out what was wrong. They called and told me that they were going to have to stop his feeding and put him on IV's and put him back in the incubator because his temperature was dropping and put him on oxygen. I thought I was losing him. That's pretty much how I felt. I didn't think he was going to be here.—Suzie, interview #1, p. 5*

### *Time Waiting*

Mothers' often depended on lab results to provide an indication of their baby's setbacks and/or progress. One mother said, "Time seems to stand still in the NICU" [while waiting on test results]. Her sentiment was echoed by other mothers, who felt a sense of urgency in obtaining lab and diagnostic test results and who desired a timely explanation of the findings. Sometimes a test like a blood gas, that only took a matter of minutes to collect and obtain results felt like it took an eternity.

*Waiting on a blood gas felt like an eternity (p. 61)...And waiting for the CF test two weeks, It seems like it takes forever when it doesn't because that's how you [as a mother] know that it's either going to be okay or not okay, if you need to worry or not need to worry. Getting test results back quickly is beneficial. Very beneficial.—Raelee, interview #2, p. 41.*

One participant's baby had a diagnosis of hypoglycemia and treatment required frequent blood glucose checks. In the section that follows she identified her frustrations with the testing procedure.

*We found that during the day when certain nurses were on, we'd have great readings. But, something would happen overnight where our readings wouldn't be so good. And we started talking to a couple of nurses that we were seeing during the day time and we found out that a lot of things have an effect on those blood sugar readings. If the area is not warm enough it won't give a proper reading. The area that you're taking the blood from, if it is not warm enough it won't give a proper reading. If they wipe [the site] with an alcohol swab, and the alcohol doesn't dry before they prick [the skin], it won't give an accurate reading. There [was] a number of factors that go into getting an accurate reading out of a blood sugar meter. And we found that some of the nurses didn't know, or maybe they thought the alcohol was dry enough...so my husband decided that every time they did a shift change, he was going to be up there and let them know—Abbey, interview #1, p. 8.*

Abbey described her desire for a consistent and accurate approach to Carlyn's blood glucose readings because the trends in Carlyn's lab results determined when she could be discharged from the hospital and Abbey described an action that she and her husband would take to ensure that process occurred.

Another participant described the interaction that took place between her baby's neurosurgeon and her family,

*He showed us the MRI of Jay's brain and he [the neurosurgeon] was very calm, he made me feel better because he knew what he had to do. Just very matter-of-fact. This is the steps that we'll take and so I knew that he knew what he was doing. So, I totally trusted him. But he showed us the MRI and he [Jay] had a subdural hematoma on his brain. Not on his brain, but in between his brain and his skull. So, he [the surgeon] said, We're going to take him into surgery today and insert a drain into his brain.—Elizabeth, interview #1 p. 5.*

### *Baby jail or Petting Zoo?*

In my interviews with the participants, they all four talked about the process that is required just to enter the NICU for scheduled visit with their baby's. The process includes: Picking up a phone outside the locked doors of the NICU, asking for permission to enter through those locked doors. Next, the



mother must then stop at the sink to scrub from fingertips to elbows, applying antibacterial gel. Then, she must proceed to a desk where ID bands are checked. Next, mothers are given a visitors badge and allowed to finally enter the world of the NICU. Once inside, the visiting time clock begins ticking. Each participant mother, in her interviews, mentioned the process and the need to go through the process at each visit (multiple times each day). However, one participant compared the process in visual terms. She said,

*The hours [and the process] for the [N]ICU make you feel like you have scheduled visitation, so your child is, is what? In, jail? Or a petting zoo?*  
Abbey, interview #2, p.22

Abbey explained, that she understood that the process was intended to provide for the safety and security of the baby, but the security check points made the experience feel like a jail and the restrictions placed on mothers at the bedside, made the experience feel like a petting zoo, because in many instances, all the mother could do was touch or stroke her baby. The process represented a barrier to the normal activities of mothering.

The narrative feature of *singularity* was identified in the participant mothers' narratives, as no mother's story replicated any other story. The transcendent themes that were addressed focused on personal experience and included: Tailored Care, assembly line, desire for normalcy, burden of depression, prior experience with illness and death.

In the section that follows, I attempt to differentiate care that valued the mother's singularity and care that does not value her singularity. For one mother, care was tailored to her needs as she described to the nurse the fear she felt

when touching her premature baby for the first time. The excerpt that follows, is about the interaction that transpired between mother and nurse.

#### *Tailored Care*

*The nurse is there all the time telling you exactly what's going on. I remember, the first time they wanted me to change his diaper, she told me exactly what to do, stood beside me, helped me hold his legs, she did everything, to make sure I was comfortable. And every other time, she would do a little less so that I could do more. And I think that's what helped the most, somebody being there that knew what was going on, that was going to help me and I knew, she knew what was best for him and she wouldn't let me do anything that would hurt him. That is what I needed—Raelee, mother of Owen, interview #1, p. 2*

#### *Assembly line*

The passage that follows is an example of what can happen when the mother's needs are not met or when the mother is treated like a number in an assembly line. Charon (2006) noted that when patients complain that care providers are not attentive or that they feel like items in an assembly line, they are complaining that their singularity is not being valued and personalized. In the following example, Elizabeth shared her frustration. She was trying to focus on her own labor while being interrupted by nurses and other care providers rushing in and out of her room, she was also hearing discussions between care providers about the number of patients that were in labor. Elizabeth also received information about the activities and noises going on outside her room, in the waiting room and corridors, which diminished her ability to focus, concentrate and relax for a pleasant birth experience. She stated later in our interview that she felt "not forgotten about but kind of neglected to be checked on" (Elizabeth, interview #1, p. 3).

*When I got to the hospital, everything started to seem rushed to me, maybe because it was my first, this was my first baby. But things just*

*started to happen quickly. I got an epidural about two to three hours after I'd been admitted. I was induced. I don't really know why. I don't know if it was for a doctors schedule or what, he [the doctor] said everything would be fine with the induction, so I agreed...Now that I look back I would have asked more questions...Then things started progressing. I started to get more contractions. The doctor didn't come in for a while. The nurses would come in and check my progress. By that time, they told me, I think all the rooms were full. It was like completely the busiest that they've had it in years. I think they said that there were 25 people in labor at the same time...It was really crazy, It was really, really busy, so you could hear people outside and I think that started to make me nervous. I thought, Where is my doctor? Is he going to have time for me? -Elizabeth, interview #1, p. 3*

Watson (2005) noted that insofar as anxiety, stress and depression, and fear are negative influences on health, then clinician-patient relationships that create these states of body-mind-spirit might be thought of as “unhealing” relationships (p. 157). A caring relationship requires presence, listening with compassion and recognizing the plights of patients. Elizabeth's story highlights the crisis in modern healthcare where routine care versus personalized care seems to lack a meaningful perspective on the very nature of humanity. Watson stressed that it is critical for healthcare providers to recognize and engage in healing practices.

#### *Desire for normality*

*As a parent of a preemie, it is hard not to compare your baby to 'normal' babies or your pregnancy to 'normal pregnancies'.—Raelee, interview #2, p.54.*

Oftentimes, without thinking, care provider perpetuate the mother's feelings of difference by making similar comparisons.

*They [care provider] said that a baby will normally correct [glucose] itself within three days. And she didn't.—Abbey, mother of Carlyn, interview #2, p. 18*

In the narrative that follows, Abbey described her desire to have photographs taken of her NICU baby that would cover, hide or disguise the wires, tubes, and medical equipment. She expressed her desire for Carlyn to look like a normal baby in a normal nursery.

*All I saw was the wires. I mean, you couldn't really see the baby for the wires and the tubes and the IV's...For a while, I mean, this My Space Baby. It's creepy. And for a while, I got real ugly with some of my friends and family and told them, none of these ICU pictures are going on the internet. None. I don't want people to see my baby like that. They are on there now because now I know that she is going to be okay...There on there[the internet] now, but for a while it was too hard for me to be able to be in a situation where other people could see those pictures. It was rough. I even went so far as to cover her and the wires so you couldn't tell that they were there. So, that I could take pictures, so that she looked like a normal baby in the normal nursery...But, it's, the pictures are very frustrating. Very frustrating. Cause you don't know, I mean, that, that your baby with wires and the tubes and everything. It just, it's hard. It's very hard.—Abbey, interview #2, p. 21*

One mother spoke about her baby's bowel obstruction surgery, he had to have a temporary ostomy placed and she was looking forward to the surgery that would put him back together [reanastomosis].

*I just wanted him to be put back together. I didn't want to come home with that [ostomy] bag. I was like, He's gonna get this off. He's gonna get it off. You know, it's the things that I could see on the outside. I wanted him to be working, you know. I could handle going home on the nasal cannula or whatever, but that part, you know, I wanted him to be normal as much as possible.—Raelee, mother of Owen, interview #1, p. 9*

As participant mothers' came and went through the doors of the Children's and Women's Hospital to visit their babies in the NICU each day, they spoke about how difficult it was to walk past the other mothers [*normal mothers*] with their [*normal newborn*] babies being loaded into their car seats for their journey home. Elizabeth described the scene,

*You see the other babies, the moms waiting out there with their flowers and all their stuff [balloons]. And the dads pull around and they're loading*

*the car seat in. And then, [my husband] came around [to pick me up at the door] and I thought, "We don't get to put our baby in yet." And then, I just had another breakdown altogether. And riding home, the dog was waiting at home, so we had to go home. But, I really didn't want to go home to see the [empty] nursery. I didn't [like] riding home with the car seat in the back empty. It's just not fair but you get over it. You know he is good hands. We didn't put any of his stuff out until he came home. My mom even said, "Do you want me to go home and take the nursery down and we'll put it back up when he...? And I said, "No." But everything was ready for him but just took a little longer to get there than we thought.*  
 ---Elizabeth, interview #1, p. 19.

After our first interview, Elizabeth shared her NICU memorabilia with me. In her photo album there was a photograph of Jay in his car seat on his final day at the hospital and a picture of the family dog Grace, in her "Big Sister" t-shirt, waiting at home for Jay's arrival.

### *Burden of Depression*

*They took her and that was the last I saw her for almost 48 hours. Which really took away from the bonding, which is why I might have some of the postpartum [depression] that I had was the fact that for the first 48 hours after my baby was born I really didn't get to see her.—Abbey, mother of Carlyn, interview #1, p. 4.*

Abbey elaborated on this point when she talked about being induced and then having to have a C-section because of her hypertension and the baby's intolerance to labor. She said,

*You feel like your robbed. I didn't feel like I had a baby. I think that's one little bit of my postpartum [depression] too." She went on to say, "I cried. A lot. A lot. I pulled away from the baby a lot. I, I for the first couple of days I went up and saw her when I could, but even looking at her, I was like, is this my baby? She also said, " you were pregnant and then all of the sudden you're not pregnant, but you don't have a baby either. It's hard, that's hard.—Abbey, interview #2, p. 8.*

*It's been really hard, I mean I've been holding up the best I can, I know that I've got people there for me and when I need to talk, they're there for me, but some things are really hard to talk about because you know your going to cry, so you just leave them alone and they build up inside.*  
 ---Suzie, interview #1, p. 16.

Elizabeth, shared similar feelings after finding out about Jay's birth injury,

*[the birth injury] just makes everything so frustrating. This should not have happened and I could totally go off on that, but that was another part of I think what caused, afterwards I think I did have postpartum depression pretty bad, not violent or anything. But just everything was making me cry. When I think back of the doctor and what I should have asked and why didn't I ask [more questions]? All the questions of why, I think just really overwhelmed me. And just made me think deeper into, why, why, why, why me? And I think, postpartum depression's pretty normal anyway but just having that happen I think made it totally worse. It made it longer for me to get over it. But I wasn't totally weird, but any little thing would make me start balling. And when I had to go back to the doctor for my checkups [at two weeks and again at six weeks], I couldn't look at him. I couldn't even speak. He would ask me, I know he felt really, really, really bad about what happened. And he'd ask me questions. I couldn't even, the words would not even come out of my mouth. Luckily, my husband was with me, so he would tell the doctor what was going on, but I physically could not even speak without just breaking down. But that's another reason why my family really got me through it. And they were there to listen to me, to let me cry. And then when he got to come home, I felt like, "Oh. I'm better now. But just to know that everything turned out alright. But I was really, it was really hard just to function everyday and go up to the hospital." The why's are what brings you down worse when you have a child in the NICU. Why me? But as soon as he came home, I was cured.—Elizabeth, interview #1, p. 23-24.*

In our third interview, Elizabeth elaborated on the burden of depression stating that,

*I was exhausted. I think I was beyond the point of exhaustion. I was still in pain by the time he got home. I really think I should have rested some at least to heal myself. But I was still in pain. Not too bad by the time he got home but still. But just beyond the point of exhaustion. But then you get a second wind when he gets to come home and you get to do the fun things, But it just caught up with me and that's when the postpartum depression kind of sat in really bad was when we finally got home and I knew I could relax. But then it was just like I was past the point of relaxing. I couldn't, I couldn't sleep. He was right there and I wanted to make sure that everything was okay. For the first couple of days it, it was a lot. It was a lot to take in. But, I didn't ever have it diagnosed or anything. I never took anything for it...It was just so many things at one time, I think it was just too much for me to handle especially because I'm such an easy going person. I think stress in general, the amount of stress that had to do with all of this was overwhelming and of course, all the*

*hormones, good Lord, leaving your body and I was just really tired and very, very emotional. Just everything good or bad, would make me just fall, you know, to the point of I can't talk anymore. And it would go up and down. I'd be fine one minute and then the next minute I can't talk to you. A lot of it was, I think had to do with anger. I was just really mad at the doctors. I was mad at one doctor. And then I had to see him a couple of times and that just made it worse. I think it was just a lot of things. It was really emotional and tired, just exhausted. I think that's what it was. But, little by little, you could tell I was getting better. And my husband could tell I was getting better and he helped tremendously. He did just as much as I did with the baby. Changing him feeding him at night. We'd take turns and he would let me sleep in the other room a couple of times just so that I could get some sleep and eventually, I just came out of it. But it's no fun.*  
—Elizabeth, interview #3, pp. 21-22.

When asked if she was able to talk to anyone about her depression, Elizabeth said,

*I never said it myself, but everyone I think could tell that it was, the depression. It wasn't me just being unreasonably emotional. And they knew that I'd been through a lot. So, I think, I kind of think it was expected. And I think they knew how to deal with it, just by being there for me and listening to me when I'd go on my long spills about who knows what that day. But I think it was obvious because it was not me. And it was weird because when I think back, I know I was happy taking care of him, and seeing him and having him home. But I also think back about the spells that I would have where I would be like, "Oh my gosh. I have never been so..." Elizabeth, interview #3, p.23.*

*I think once [Jay] got his stitches out, we could give him a normal bath and he started to become more normal and then when I knew he was going to be okay after the visit to the neurologist. Everything was fine. I think a combination of that and letting me talk about it, I think that all of a sudden, I was like, "Okay. Everything, everything will be alright."—Elizabeth, Interview #3, p. 24.*

### *Prior Experience with Illness and Death*

When Owen received the diagnosis of ROP, Raelee, called a friend who had a baby that was in another NICU and she had to have eye surgery. In the following except, she described that conversation.

*And so, I called her [a friend] to ask her how, what happened to her baby and she said, "Oh, she went from everything is fine to stage three or four ROP" And her little girl is blind, well, blind in one eye. And I thought, Hmm, great, same thing's wrong with Owen...And so, but my friend's*

*daughter, when they tested her [for ROP] it was like two weeks before they did surgery on her. And when they came in and said, We're gonna do it [Owen's laser surgery] in two days, I thought, you know, Maybe this will be my saving grace right here since they're not gone put it off.*  
 —Raelee, interview #1, p.12.

Suzie's experience was also touched by her previous experience. Her grandma died two months prior to the birth of Terrell. Suzie's experience came to light as she shared her NICU memorabilia with me at the end of one of our first interviews. She said that one of the most meaningful things that she kept was her baby's crib card and attached to it, was an Angel of Remembrance pin that symbolized her grandma. She told me that one night while Terrell was in the NICU, she had a dream.

*I woke in the middle of the night and started crying, I had a dream that my grandma had walked into the NICU and she was sitting there rocking him [Terrell], I knew he would be alright. She was watching over him—Suzie, interview #1, notes on memorabilia, p. 9.*

The narrative feature of *intersubjectivity* was described in participant mothers' narratives as they spoke about their relationships with others and the responsibility they felt toward their baby. Some examples of transcendent themes that emerged include the following: Encounters with nurses, Out of the loop, earned Trust, butterflies and curtains, protecting the family, family support.

#### *Encounters with Nurses*

One participant described that nurses would call her with good readings and they would call her with bad readings. She provided the following example of how wonderful it was to get good news. The nurse called and said,

*Hey! We had a great reading." "The nurses would get excited and you could hear the excitement in their voices which made you even happier because you knew they cared.—Abbey Interview #3, pp. 10-11.*



Elizabeth spoke about her relationship with the nurses as they helped her become more familiar with caring for Jay with his ventriculostomy and associated equipment. She said initially she was afraid to feed him and burp him with the ventriculostomy because the drain had to stay level and she was afraid that she would shake him too much.

*When he [Jay] laid back, there was plenty of slack in the drain, But, when you sat him up, I was afraid I'd pick him up too fast or that I would shake him too much, I burped him because the nurses, they make you. She [the nurse] said, "You're going to have to do this when you go home. So let's practice." And I'm like, "Aaah." Even if I don't want to [it], She [the nurse] said, "I'll help you." She would stand right there with me, if I needed help. If I started to look like I was overwhelmed. She said, "It's okay." They helped me through it, but I think it was mainly his drain. I just didn't want to shake him up...But I burped him, fed him, and changed him. I learned how to give sponge him down, he couldn't have a bath until his stitches were out for a couple of days. So thankfully, they taught me how to do that. [This story was told while Elizabeth shared pictures of her holding Jay].—Elizabeth, Interview #1, p. 18.*

*Another participant described how nurses brainstormed to help her come up with ideas for how to keep Jay's head elevated at home following his VP shunt placement.*

*After surgery [VP shunt placement] the surgeon wanted to keep Jay's head elevated. And I was thinking, when I get home, should I prop up the crib or what? So, someone thought of those little bouncy chairs and they were like, no, that's too wobbly. So they [nurses] tried different things in his crib and then someone said, What about a boppy (a C-shaped supportive pillow)? And so, all the nurses tried to think of something to put him in, to keep his head up. Everybody was kind of brainstorming. That was kind of fun to see everybody, trying to think of something to do. —Elizabeth, interview #2, p. 20.*

### *Left Out of the Loop*

Regretfully, communication between mother and nurse and/or mother and physician in the NICU is not perfect and can be impaired for a variety of different reasons. This study, highlighted several ways that mothers felt left out of the

loop of communication and decision-making while in the NICU. In the first example, Raelee, mother of Owen, described a conversation with her primary nurse.

*I remember going back in his room [after surgery] and he was a little puffy already and then for the next two or three days, he didn't use the bathroom at all. I watched him blow up. I think he went from two and a half pounds to five pounds, that was probably the worst, just seeing him puffy...I mean, he was so swollen and all they [care providers] would say is, "He needs to go to the bathroom". And I didn't understand all that, which now, I guess it's best I didn't, until probably two or three weeks post-op. That's when Allison [pseudonym of primary nurse] told me just how serious he was. She said, "I was wondering if you were just so strong coming in here everyday and [you] would go home and be a basket case". She [Allison] said, "that's what I thought you were doing". And I said, "I didn't have a clue". I said, "ya'll [healthcare providers] didn't tell me". And I said, "We'll, maybe it's best that I didn't know"...And to me, that's not a mistake on their part, not telling me everything that was going on. It was a blessing because I didn't need to know what was going on with him. I needed to know he was gonna be fine. And I just remember them saying, "He's got to use the bathroom"...I didn't realize in life and death situations his kidneys have to start functioning. But later, that evening he went to the bathroom [urinated]. And then after that everybody thought he's going to be fine now.—Raelee, interview #1, pp. 7-8.*

*Later, Allison, explained to me that he was on the edge of death that day. She said, "we've had other babies in here that didn't make it past the bullfrog [swollen] stage", is what she called it at the time. She said, "You're lucky." And I guess I was. But then, that's when I realized, we are going to go home one day. —Raelee, interview #1, pp. 7-8*

Raelee story highlights many breakdowns in the communication process as well as potential barriers to communication. As this case illustrates, nurses and physicians may believe that a particularly critical situation has been communicated to a mother, when in reality, it has not. There was obviously a lack of communication in this case. Barriers to communication and understanding are complex and are too numerous to name here. However, I will attempt to highlight a few of the barriers that I perceived played a role in this case.

First, care providers, sometimes take for granted that mothers understand body systems and physiology. This mother, like many other NICU mothers, did not have a medical or nursing background and she had little experience with illness and healthcare; she could not be expected to understand the seriousness of her baby's post-op condition without the help of care providers.

Second, mothers often rely on external clues like body language, tone of voice and facial expression from care providers to signal the seriousness of their baby's condition. However, in this incidence, the nurse was an experienced NICU nurse with a calm and composed body language and tone of voice, even in the most serious of situations. The nurse's body language could have been another contributing factor in this lack of communication. The calm and composed body language of the nurse, led Raelee to believe that everything was going according to plan.

Another barrier to communication is silence, many times mothers are silent or passive; not because they don't have any thing to say or contribute but because they are overwhelmed and paralyzed by fear. Mothers, do not want to get in the way of care providers. Mothers may also be afraid to ask for more information because they don't want to seem too demanding, uncooperative, controlling because they fear their behavior might impact how the care provider views and provides care to the baby. Other mothers may not know what questions to ask.

Communication in this case was lacking on many different levels. It is not only the responsibility of the nurse to provide the mother with the information that

she needed. Owen had both a primary neonatologist and a pediatric surgeon involved in his care and they too had failed to adequately communicate the seriousness of Owen's condition to his mother. Later, when Raelee found out what had happened she said,

*We'll, maybe it's best that I didn't know"...And to me, that's not a mistake on their part, not telling me everything that was going on. It was a blessing because I didn't need to know what was going on with him. I needed to know he was gonna be fine.—Raelee, interview #2, p. 42.*

Even so, Raelee did not consider the lack of communication and disclosure a mistake, and instead believed that it was a "blessing in disguise". There is much to be learned from her experience. For example, Raelee said,

*The first thing I thought was, "Thank you for not letting me know." Sometimes the not knowing is better for you, which for me it was [better]. But then I thought, "I didn't know how bad it was." And if something would have happened, I'd have been crushed. It would have been horrible. But then after that two weeks time, you look back and say, "I can't worry about that now." I just remember thinking, "Thank you for not telling me." At first I said, "Allison, ya'll should have told me". And Allison, said, "We thought you knew. [we thought] you would pick up on it." And I said, "I knew he was sick, but I didn't ever think sick enough that, he's not going to make it this time." I guess, realizing it later, it was like "Ugh!" My heart just kind of stopped when she told me how bad it was. I remember going home and thinking, "Wow! We might not even be here to day." But that was my saving grace, not knowing. Now, I look back and think, "I'm glad I didn't worry about it because I would have worried for nothing again. Everything was going to be fine". So it was kind of a relief, I didn't know. I didn't know how bad it was.—Raelee, interview #2, p. 42.*

Healthcare professionals often find it difficult to talk about the uncertainty associated with premature or gravely ill newborns. However, as evidenced by these mothers' experience, it is critical for healthcare providers to provide opportunities for difficult discussion about illness and the possibility of death to take place. Finkelstein, Holtzman and Smith (1997), noted that disclosure is an important mechanism for the patient (mother in this case) to maintain a trusting

relationship with her healthcare professionals. Disclosing sensitive information to the mother is difficult but necessary and ethically responsible professional behavior.

Charchuk and Simpson (2005) addressed some of the challenges associated with disclosure of information and noted an approach to disclosure that allows the patient to take control and decide how much and what information they want and are ready to hear. Their approach suggested, if parents are not ready to hear about the diagnosis and the uncertainties that are associated with it, then, it is important for care providers to offer repeated opportunities for discussion. Their approach encourages care providers to ascertain from the patient how much he or she wants to know. The approach should be repeated until the parents have attained all of the information they want and need. The process they suggest is one of repetition and reiteration, allowing parents to influence the flow of information.

Watson (1985) noted that cultivation of sensitivity to self and others is an important carative factor because those who are not sensitive to their own feelings find it difficult to be sensitive to the feelings of others. According to Watson, people who repress their own feelings may be unable to allow others to express or explore their feelings particularly with difficult and painful issues surrounding conflicts, death and loss. Watson also noted that educational and practice situations in nursing often prevent or at best discourage the nurse from being too sensitive to or getting too involved with another's feelings. The nurse may then respond or react by protecting and insulating herself from her own feelings. As a result, Watson, noted that nurses often form impersonal, detached

relationships hiding behind a so-called professional character armor. I am not sure if this factor played a role in the above example but it is certainly possible. According to Watson, the nurse often deals with her own insecurities and feelings by camouflaging potential conflicts between nurse and patient. However, the conflicts are not resolved by ignoring them as the previous example illustrates. As Raelee later noted, she would have been “crushed if something had happened.” She would have also been ill prepared to cope with the crisis and potential death of her baby, because she was not offered adequate situational support.

### *Earned Trust*

After witnessing her baby extubate, turn blue and have to be resuscitated and reintubated, Raelee said,

*you just have to trust them [care providers]. That's the biggest thing. I mean, if you can't trust the people working in there, then, and, they have to earn your trust.—Raelee, interview #1, p. 5.*

When asked to elaborate on the issue of earned trust. Raelee said,

*I had to see how they reacted to him, how much they cared for him and then the way they talked to us.—Raelee, interview #1, p. 5.*

Watson (1985) noted that caring must be grounded on a set of universal human values including kindness, concern, and love of self and others. According to Watson, relationships of trust cannot exist without caring based on a value system that affect the encounters between nurse and other person. “Altruistic values and behavior bring meaning to one’s life through relationships with other people” (Watson, 1985, p. 11). Caring consists of humanistic-altruistic feelings and acts that promote the best professional care and the most mature social contributions and for that reason, Watson considers the formation of

humanistic-altruistic value systems the first and most basic factor for the science of nursing (p. 12).

### *Butterflies and Curtains/Witnessing the Suffering of Others*

Through participant narratives, I became more aware of what is witnessed through a mother's eyes while in the NICU. From participant interviews and journal entries, it was apparent that all participant mothers in this study were touched by the suffering of others in some way. In the passage that follows one participant wrote,

*I think a baby died today. I hope God is comforting that family in their loss. I can't imagine what they are going through. Please be with Owen God. I can't live without him.*—Raelee, journal entry, January 19, 2008.

In the NICU there is a practice of hanging laminated signs, picturing colorful butterflies on the doors entering the unit, when there is a baby that is near death or dying. The practice was designed to be a reminder to healthcare staff that parents were in mourning and therefore, staff needed to be extra careful about what was said: no laughing, joking or loud talking was allowed in the area. However, Raelee brought it to my attention in her interview with me that parents also quickly learned the meaning of the curtains and butterflies and what they symbolized.

*The part of the NICU that I never got used to was seeing curtains [intended to provide privacy] up around babies or seeing the babies in the isolation rooms [also a place intended for privacy] and then people calling the family; that stuff, I never could get used to it because I always thought, that could be us. I mean they could be calling my family in right now. I remember the first time I saw the butterflies [signs] up and I asked somebody, Why are there butterflies up today? And they were like, there is a baby that is really sick...I got used to all the sounds, all the monitors, all the people in and out. I got used to all that, but I didn't get used to seeing the butterflies up and seeing the families coming in and out. I couldn't get used to that. I don't think anybody can though. That was the hard part.*—Raelee, interview #2, p. 7.

In the passage that follows, Raelee, provided an example of her experience with curtains and butterflies.

*She was in the room across the hall from Owen, I remember, when babies are really sick, you see the doctors and nurses A LOT at their bedside. You can tell when a child is starting to get sick there or I can. And so, I knew something wasn't quite right with her, and I could hear the parents crying and talking and that kind of stuff. But, the day that I walked in and they had the curtains completely closed, normally you can see in through the glass, and when the curtains were closed and I saw the butterfly on the door, I thought, something's wrong. And I remember asking the nurses, I said, I know you can't tell me anything, but is that baby gonna be okay? And she said, 'That baby is going to see Jesus today'...But it's hard to see that, because you think, What if that was us? What would we do? So that was the hard part.—Raelee, interview #2, p. 8.*

Raelee also shared a journal with me that she had kept about her NICU experience. In one of the entries she wrote, "I think a baby died today."

*This makes the third death that I have witnessed in the NICU, My heart goes out to these families because I know how difficult it must be to lose a child. One thing I have learned through all this is to put things in God's hands. It has worked for me so far! —Raelee's journal entry, Feb 19<sup>th</sup>, 2008.*

Another participant described a situation in which she overheard a conversation between neighboring parents and their nurse, they were at the bedside beside Terrell

*I know there was one baby that was next to Terrell. He, they basically sent him home on tube feeding and told 'em [the parents] sorry, that he wasn't going to make it and for me just to hear that, them tell the parents that, I mean that was bad because I [thought], What would happen if I was to have to come in and hear that. Sorry. Terrell, he needs to go home now, you need to love him while you can because he's not going to be here. That was really hard. Just even hearing it, it wasn't my baby but it was really difficult. —Suzie, interview #1, p. 3.*

Watson's (1985) existential-phenomenological carative factor "can teach one the best way to understand another human being is to get into his or her



Weltanschauung, to look at the world through his or her eyes" (p. 207). Raelee's own account of bearing witness to the suffering of other fellow NICU mothers and families in her story of butterflies and curtains certainly opened my eyes to the involuntary and internal human predicament that many mother's in the NICU experience. Suzie's story also brought awareness to the difficult human predicaments of life. That is, life is at times uncertain, unfair, unjust and there is no escape for nurses or patient's from issues of life and death.

### *Protecting the Family*

*They [family and friends] don't fully get the whole thing. I mean, just how bad it is. Because like I said before, you wanna be that rock. You wanna be oh, it's okay, I know she's gonna be okay. So, it's okay. Everything's okay. Well, I'll be alright. We're gonna get through this. But you have doubts.—Abbey, mother of Carlyn, Interview transcript #3, p. 4.*

Another participant, Raelee, maintained three separate journals, each with different purposes. She had one journal that she would write in while in the NICU about her true feelings and reactions to her experiences. Even though, she did not share the information contained in that journal with me, she indicated that there were thoughts in that journal that were just too painful to share with others but she found it helpful to write them down.

She had a second journal that she kept for her baby. In that journal, the focus was the baby's life story. She outlined the daily happenings in the NICU. She kept track of the baby's weight, progress, and setbacks. She wrote letters and notes of encouragement to her baby. She told him about all the people that loved and cared for him while he was in the NICU.

In a third online public journal site ([www.babysites.com](http://www.babysites.com)), Raelee posted progress reports for other family members and friends who wanted to keep track

of the baby's progress but who did not have access to the NICU. Raelee noted that in this online public journal she tried to remain positive. She did not want others to be worried about her; she wanted their attention focused on the baby. She also wanted to protect others dear to her from the emotional rollercoaster of the NICU that she was experiencing.

In addition to journal entries, Raelee, posted a photographic diary documenting her baby's journey through the NICU. Friends and family then had the opportunity to respond by posting words of encouragement and prayer to both mother and baby (Email communication with Raelee, mother of Owen February 3, 2009).

Elizabeth, mother of Jay, also maintained an online journal and photographic diary at ([www.flicker.com](http://www.flicker.com) and [www.babyhomepages.net](http://www.babyhomepages.net)) to share her experience and Jay's NICU story with family and friends.

### *Family Support*

All participants in this study spoke about the importance of family support throughout their stories. Raelee, described one meaningful moment with her mother while at Owen's bedside in the NICU. In her journal dated January 5<sup>th</sup>, 2008, Raelee writes of her mother,

*She read to you, sang to you, and talked to you. I know she was trying to set an example for me and show me how mothers have to be strong for their children...Later that day I read you a book and said a little prayer and promised to return the next day.—Raelee, journal entry, January 5, 2008.*

Another mother shared photographs of her family with me and told me about the important role her family played in helping her to heal. She said,

*I couldn't have made it without my family. We're really close anyway, but*

*this brought us unbelievably closer. My mom and dad were there [for me] from the beginning. I finally, I physically was just drained and exhausted. I should have been taking time to heal myself, and I wasn't and it finally caught up to me. I was just in agony. I was in so much pain. So, they said "You go home for a couple of days and rest and sleep. And you heal yourself. And by that time, my milk had come in and I was kind of glad that I wasn't breastfeeding because I think it would have been just really too much on me to have to pump and bring it up there and, make sure his supply was up. So, I had to let the milk subside and that was extremely painful. And then the episiotomy, I had to let that heal finally. I went home and healed for two days and mom and dad stayed up at the hospital the entire time that I wasn't there. I just couldn't have made it without my family. And my husband was amazing. My sister, my aunt, my uncle, everybody was just around me the entire time. Whatever I needed, whatever the baby needed. They were amazing. All of them. And I think they were in as much pain as I was when they found out what happened to Jay. They were wonderful, thank goodness. —Elizabeth, interview #2, p. 21.*

The narrative function of *ethicality* was often revealed in the moral tales told by participant mothers'. Their stories often expressed their values and concerns. Mothers' stories often spoke of the messy and confusing problems that defy technical solution that are of greatest human concern. The following are transcendent themes that represented mothers' moral tales: Valued responsiveness, vulnerable aspects of life, demonstrating hope and faith, desire to help others.

#### *Valued Responsiveness*

*I liked how in the NICU, the doctors worked as a team. Like, I knew if my primary doctor was not there that somebody would come in and help me and they knew exactly what was going on with him—Raelee, mother of Owen, interview #1, p.3.*

*I liked the way there was a fast response to him—Raelee, interview #1, p. 3.*

*You [Owen] had a wonderful nurse today. She was very gentle with you and talked to you a lot. I love that because it makes me feel better about leaving you—Raelee's journal entry January 16, 2008.*

### *Vulnerable Aspects of Life*

One participant described the scene when her premature baby extubated,

*My thought was he, I mean, I knew he was dying, that's, I mean, he couldn't breath. And I told Mama, I said, I can't sit in here. I cannot watch him die.—Raelee, interview # 1, pp.4-5.*

She then explained that she left and went outside the NICU. Later, nurses returned to her to tell her that Owen had been reintubated and that he was going to be fine. But the whole time, Raelee said she was thinking,

*He's not gone make it, I saw him. He turned blue. He's not gone make it. But Raelee said she kept thinking, "He almost died...He could die with any minute. And I guess, the first time that it happened was the time that I realized, he's got to have this [breathing tube and ventilator] to live.. —Raelee, interview #1, pp. 4-5.*

Elizabeth described Jay's Baptism:

*Father Tom came in and you're only supposed to have two visitors in there, but they let my grandma come in, she's Catholic and she pretty much raised us Catholic and I wanted her to be there for, his baptism. So, he baptized him there [in the NICU] and it was just sad because we didn't know if he was going to make it. So, it was nice that they do that...So, I'm glad that we did that. It was just sad to think, why we do it. I think at the time, it didn't really hit me. I was like, let's get him baptized, but then after they wheeled him out to go to surgery, I thought, that might be the last time we see him, so that was really hard.—Elizabeth, interview #2, p. 21.*

Later, after Jay came back from surgery following the ventriculostomy placement. The neurosurgeon spoke with Elizabeth and her husband.

*He told us that he had never seen an intracranial pressure (ICP) that high in an infant before. That he should not have made it. That that pressure was just unbelievable. And of all [his] years of experience [the ICP was the highest]. We thought, "that had to be our son that broke the rules", So, it was amazing altogether. "He is definitely a miracle." —Elizabeth, interview #1, p. 11.*

Susie described her experience as transformative.

*It's [the NICU experience] been very [life] changing. Very meaningful. I get a whole new life and the way I do things, the way I act, my behavior in a*

*lot of different ways, how I treat other people because you never know when things will happen or something serious is going to happen. You just don't know when they're going to leave you or when you're going to be here forever.*—Suzie, interview #3, p. 1.

Watson (1985) recognized the gratification of human needs as an important carative factor. This is recognized in mothers' stories about the vulnerable aspects of life. It is important for the nurse to help the patient gratify his or her needs in the order of importance, from lower order needs to the higher order. For mother's in this study, their needs varied and changed throughout their NICU experience. For example, Raelee's primary concern initially (as expressed in the above excerpt) was that the healthcare team intervene to provide an airway, a basic life life-saving and life sustaining need. Elizabeth desired spiritual guidance and comfort at Jay's Baptism. Suzie, expressed transformation at the end of her baby's NICU course, she said her baby's discharge from the NICU signaled the beginning of a whole new life for her. She recognized the importance of relationships and the uncertainties that life brings, as she reached for higher level goals of growth, maturity and self-actualization.

#### *Demonstrating Hope and Faith*

Mother's oftentimes turned to faith to get them through their most difficult and trying experiences. Raelee described, her feelings following Owens, birth and surgery for bowel obstruction:

*If the Lord has brought him through, you know, premature birth and now this major surgery, then he is going home.*

*This has taught me many life lessons, one of those being to rely on God no matter what comes our way. He has protected your daddy and me and you over the past 14 weeks. We are so thankful for that.*—Raelee's journal, April 9, 2008.

Suzie demonstrated hope in the following excerpt:

*At first I was real scared about the pregnancy, but now, I just look at it as a blessing. God's put him here for some reason and I'm here to take care of him and obviously he thinks I can do it. So I kind of hope for the best.---*  
Suzie, interview #3, p. 2.

Elizabeth gave thanks during her nightly prayer with Jay:

*Everyday, I see him [Jay], his personality I think the rest of his life he's going to be breaking rules...He's really happy. He's like the happiest baby I think I've ever seen. And maybe he knows he made it, when he probably shouldn't have and he has lots of reasons to be happy. So he doesn't cry a lot, he's just really giggly and just a wonderful baby. And he really is a miracle and you think about it everyday. And I do. Everyday. When we say our prayers at night, I always thank God for that.-*  
--Elizabeth, interview #3, p. 16.

The instillation of faith and hope is one of the carative features described by Watson (1985), Watson, stresses that nurses and other health professionals must not ignore the important role of faith and hope. It is important to recognize and respect what is meaningful and important for the patient. Therefore beliefs should not be disregarded, faith and hope should instead be encouraged for their healing properties. Even when cure is not possible, the patient can be offered comfort and support by care providers as they bear witness to the patient's pain and sorrows.

#### *Desire to Help Others*

One participant said after a while in the NICU, when we would see other parents freaking out, she would say to them,

*It's okay. You know, they'll take care of it. Don't worry about it. You know, after a while, you get so comfortable you just think, "You'll be fine." "Here I am giving pointers to everybody else---Raelee, interview #1, p. 5.*

In a journal entry shared with me by Raelee, mother of Owen she described Owens grandmother's visit. At the time, Owen was in one of the semi-

private rooms in the NICU, he shared the room with his neighbor Neal [pseudonym].

*Grandmother came this morning. She and I came to visit you. She read you a book and sang of course. She stands in the middle of the room to read to you so Neal, your neighbor can hear. He doesn't have family that visits and has been here for a while so we want him to know that we love him and we are here for him.*—Raelee's journal entry, Jan 23, 2008.

Watson (1985) noted that the science of nursing, includes both humanistic and scientific approaches that help the nurse respond to the patient's need for holistic health care. Furthermore, Watson's ten primary carative factors offered a structure for studying and understanding nursing as the science of caring. In the current study, I first listened to stories told to me in qualitative interviews by NICU mother's and then began to delineate ways in which nursing care was or could have been organized to improve the mother's NICU experiences.

### Summary

This study was grounded in narrative perspectives and was conducted to uncover the mother's experience of having had a baby requiring care in the NICU. The purpose of this study was to describe and interpret mothers' NICU experiences and to sensitize health care professionals about the importance of mothers personal experience stories.

The NICU experience for the mother began with her birth experience or the incident that led up to her infant requiring care in the NICU and her experience extending beyond the NICU with further concerns about the health and well-being of her baby.

In this chapter, I illustrated how I constructed and managed over 600 pages of interview transcripts using data analysis combining the structural

approaches of Labov and Waletzky (1997), and Riessman (2008), adapted from Gee (2005). The analysis also identified five narrative features and transcendent themes drawing on approaches outlined by Charon (2006).

The first level of reflection identified the following core narratives: enchantment, disenchantment and re-enchantment stories. Enchantment stories were the stories mothers told about their hopes, dreams and ideals for their first pregnancy, birth and baby. Disenchantment stories were stories that mothers told when things did not go as planned and babies required care in the NICU. Re-enchantment stories were stories told by mothers about their attempts to create normalcy in the chaos of the NICU. These stories were also about the mother's efforts to create new ideals, hopes and dreams as they created memorable moments and celebrated each new milestone.

The second level of reflection revealed descriptions of five narrative features and transcendent themes. The first narrative feature of *causality/contingency* illuminated the following themes: *tears in the fabric of daily life, mourning life as imagined, questions of why? and search for answers*. The second narrative feature of *temporality* illustrated the following themes: *rollercoaster, waiting, baby jail or petting zoo?* The third narrative feature of *singularity* identified the following five themes: *tailored care, assembly line, desire for normality, burden of depression and prior experience with illness and death*. The fourth narrative feature of *intersubjectivity* gleamed the subsequent themes: *encounters with others, out of the loop, earned trust, butterflies and curtains, protecting family and family support*. The fifth narrative feature of *ethicality*,



revealed the following transcendent themes: *valued responsiveness, vulnerable aspects of life, demonstrating hope and faith and desire to help others.*

This research makes a plea to health care providers that through narrative understandings and observation of Watson's carative factors, we can maintain a better balance between the highly technological aspects of the NICU and also achieve therapeutic relationships with patients by embracing our duties toward individuals. Mothers' stories have the potential to provide moral education, reminding care providers who NICU mothers are, what concerns them and why certain care practices are valuable. These care practices can help guide care providers in what to do next and how to live now. Through narrative understandings, mothers' stories can help sort out what makes some care practices better than others. Implication for health care professionals in practice, education, healthcare policy and research are described in the Chapter VI.

## CHAPTER VI

### DISCUSSIONS AND CONCLUSIONS

#### Introduction

The purpose of this study was to describe and interpret mothers' stories of their NICU experience and to sensitize health care professionals to the importance of listening to mothers stories. Initially, the aim was to uncover mother's experiences of having a baby in the NICU. However, the four participant mothers did not limit stories to the NICU experience. Mothers often began their stories by telling about the experiences that occurred during their pregnancy and birth that led up to the NICU experience. Mothers then provided detailed stories of their NICU experiences. They also provided stories that placed their experience in the context of their life goals, plans and dreams. Therefore, this study encompassed much more than the NICU experience. Although the experiences of participants varied, common story types and themes emerged from a collection of richly textured data that included interview transcripts, photographs and NICU memorabilia.

The method undertaken did not follow a step by step set of rules. Instead the narrative approach used a variety of "thinking tools" to investigate the qualitative research questions and allowed for adaptation, innovation, and creativity in the process.

Analysis of data began after first listening and reading verbatim transcripts repeatedly. This careful reading generated three distinct story types. Participants did not necessarily bring the following core narratives up in the order that I have arranged them for discussion: *enchantment*, *disenchantment* and *re-*

*enchantment stories*. The first core story that I identified was the story of enchantment. *Enchantment stories* emerged as mother's shared their hopes, dreams and ideals for their first pregnancy, baby and birth. *Disenchantment stories* resulted when mother's enchantment story suddenly went awry or some event occurred that interrupted or disrupted the mother's plans for her first pregnancy, birth and baby. As participant mothers reflected on their disrupted plans, dreams and ideals, they often viewed their experience in a different light, reframing the disenchantment story into one of *re-enchantment*. In *re-enchantment stories*, mothers reconstructed their life story to fit a set of life circumstances different from those originally anticipated. Re-enchantment stories helped to heal the mother's sense of profound disruption and place the disruption in perspective in her life.

Analysis continued as narrative features were identified along with its transcendent themes. The five narrative features included: causality/contingency, temporality, singularity, intersubjectivity, and ethicality. Transcendent themes were illustrated by participant's narrative excerpts and quotes. The results of the study support the importance of stories in providing comprehensive understanding of mother's NICU experiences.

I began this study because I was interested in learning more about the participant mother's search for meaning following her NICU experience. I also wanted to explore the moral concerns that were expressed in mother's stories of their NICU experience. My hope was that attention to NICU mothers' stories would help improve care by highlighting what was most common, most taken-for-granted and what concerned NICU mothers most.

This narrative study enabled me to look closely at how mothers attempt to make sense of the breach that exists between hopes, dreams and ideals for their first pregnancy, birth and baby and their NICU experience. It also allowed me to notice the moral concerns expressed by mothers in their stories.

This study has shown how mother's stories change over time.

Enchantment stories stem in part from the preferred American narrative structure of the proper and expected trajectories of pregnancy, birth and fetal development. Disenchantment stories referred to a breach between previous expectations and human circumstances of vulnerability, unpredictability and chaos. Disenchantment stories did not follow predictable, coherent or linear paths. The preferred American narrative of progress and success was suddenly shattered when pregnancies were cut short by maternal illness, infant illness and an associated NICU admission. In this study, birth stories were interrupted by a variety of factors including, maternal illness, fetal intolerance to labor, prematurity and birth injury. The four participant mothers' plans for bringing home baby were suddenly dashed by the NICU admission of a fragile newborn. The effects of disenchantment stories on the mother often presented themselves both physically and mentally; as the stories of disenchantment have demonstrated in this study. NICU mother's shared stories overwhelmed by anxiety, depression, and often paralyzed by fear. Mothers' stories changed again, once it reframed unexpected events and began to draw on culturally salient images like being positive, maintaining strength, and fighting through. This change was also reflected in the mothers' expressed desire for normalcy and her desire to adjust or modify hopes and dreams.

The NICU experience prompted mother's efforts to make sense of the unexpected experience. This was accomplished as they mourned the life that they had imagined for themselves and their baby. They began asking questions and began a search for answers independently from the information provided by care providers. For one participant, the use of metaphors helped her relate the frustrations of the NICU visiting hours to care providers. Abbey, mother of Jay, described the NICU entry process as visiting a baby jail or petting zoo because of her restrictions while in the NICU concerning her own baby. The metaphors that this participant used helped her to create new understandings of the phenomenon of her experience. The mothers' ability to adjust and modify hopes and dreams also reflects the preferred American narrative structure.

#### Narrative Meanings

Participants constructed stories to convey a specific perspective of the NICU experience. It was meaning not necessarily truth that was conveyed in the mother's stories as they constructed ideas to be entertained by listeners. These stories provided insight into the important personal truths, which are vitally important to providing appropriate and timely nursing care. In the current study, each mother's past hopes, dreams and plans conveyed significance in the telling of her NICU experience. Each participant's NICU experience illuminated many of her values and beliefs, and her view of the future was full of new intentions, goals, hopes and dreams. But for all four participants, their stories were unfinished and muddled as the long term future of the baby remained unknown.

## Narrative Ethics

After identifying narrative types and narrative features with transcendent themes, I began to turn to the moral concerns embedded in participant's stories. I was particularly interested in how mothers story the ethics of their daily life. I found Walker's (2007) expressive-collaborative view to be a guiding source as she highlighted how experience plays important roles in our *moral understandings*. She writes,

They [reports of experience] bear information on how modes of living *seem* and *feel* to the people living in them. As important, recognition of the need to hear and readiness to credit reports from all locations within a social world are themselves moral positions because of the known significance of *silencing* as a weight-bearing feature of unjust arrangement. When voices break through and are heard from places of strategically and systemically imposed silence, a moral-social order is already shifting. (Walker, 2007, p. 264)

For study participants, moral aspects of narrative reconstruction were identified in stories that mother's told about values, identities and relationships. I will elaborate briefly here on the moral force of identities.

### *The Moral Force of Normalizing Ideologies*

This study has tried to show the moral force of normalizing ideologies for mothers who do not get to experience the nine month pregnancy, the natural birth experience and the full term healthy baby but instead see themselves as different from other mothers'. Mothers identified conflict between the desire for normalcy and acknowledgment of difference again and again. Stories that

participants told about pregnancies cut short, birth plans interrupted and maternal and infant illness brought attention to their sense of difference from other “normal” mothers. I chose to highlight the mothers’ expressions of difference as well as her desire to return to normalcy because it seemed to be a common thread throughout the four participant’s narratives.

A desire to return to normalcy played a role in the mother’s ability to reframe her story from one of disenchantment to one of re-enchantment. When mothers experienced disenchantment they also experienced lack of control, feelings of powerlessness, and restrictions placed on what they perceived to be the normal activities of mothering. As mothers struggled to reframe their disenchantment stories, they engaged in efforts to create a sense of continuity following the NICU experience. They also struggled to regain power and control over their lives and the lives of their baby. As these changes took place, mothers experienced internal conflict in that they wanted the baby to make progress toward discharge but they also did not want the baby to be discharged home before they were both ready. Mothers expressed ambivalence about the babies’ uncertain long-term future, and at the same time they experienced transformation in the process as they began to appreciate life with all its uncertainties.

#### Implications for Nursing Practice

This research has critical moral and practical implications. To better understand how we should live, as practitioners, in clinical practice, we need to be willing to invite our patients to express their values, beliefs and judgments about their illness experiences. We should also be willing to hear what patients have to say about our clinical decisions and actions. In this way, their stories

become transformative for practice as they reveal what is needed, most valued, and most taken-for-granted. Failure to acknowledge or recognize the important stories of patients in our care risks harming the patient. Personal experience stories, like the ones shared in this study, are critical to care because they function as agents of understanding (Sandelowski, 2004). In clinical practice, stories call for a response. As care providers listen, a healing presence is offered and in this caring moment a moral exchange occurs (Mattingly & Garro, 2000; Watson, 2005). Attention to narratives in clinical practice illuminates some healing aspects of patient-centered, therapeutic and caring relationships that are likely to be neglected, particularly in a highly technological world, like the NICU, where evidenced-based practice is the mantra.

#### Implications for Nursing Education

Story telling offers potential dividends to nursing education. The narrative path toward clinical competence offers a practical means to bridge the considerable divides that separate and limit the effectiveness of members of a vast assembly of health care professionals (Charon, 2006). The primary struggle for nursing has been to develop a generalizable knowledge base through the use of evidence based approaches to practice without sacrificing regard for human dimensions and concerns. Incorporating narrative approaches to education and practice can help strike this necessary balance. The approach encourages creativity and reflection in practice. The approach requires an intensive interaction and an awareness of how to relate to people in their most difficult and troubling times.



A narrative approach to education offers opportunities for educators to assist students in developing sensitivity to self and others. Narrative insights into clinical practice can help strengthen specific skills of attention, empathy, collaboration and respect for another person's perspectives. These tools help students learn to care amid suffering (Eifried, Riley-Giomariso, and Voight, 2001). As students bear witness to another's suffering, the caring presence of the student will diminish the other's suffering, thus promoting nurturing and trusting relationships (Watson et al). Watson (1985) noted that caring is central to nursing and can only be demonstrated and practiced interpersonally. A narrative approach to education and practice offers compelling evidence for care. However, it does require effort, discipline, commitment, patience, compassion and wisdom but it also encourages this interpersonal connection with others and thereby offers opportunities for health, healing and transformation in the healthcare setting.

#### Implications for Nursing Research

Story telling is integral to research. Several traits distinguish narrative inquiry from other forms of research. Storytelling allows the world of the patient to be explored. Holloway and Freshwater (2007) noted that

Carrying out narrative research is doing both art and science: making art is a creative act concerned with generating an effect-be it beauty or surprise. The artistic goal in narrative research adds creative aesthetic and craft elements but it also enhances practice. (p. 3)

Kvale (1996) also noted that the qualitative research interview is a construction site for knowledge. As was demonstrated in the current study, a

narrative approach to inquiry allowed a space for an inter-change of views between the researcher and the participant about a mutual interest area of interest, the NICU experience. At our face-to face meetings, an interaction transpired and a relationship developed. Through the relationship and interaction with participants, knowledge was gained about the discontinuities that existed between their stories and experiences. Experiences were not as linear and coherent as the stories tended to be when looking back on an experience. Sandelowski (1991) recognized that a "life event is not explainable while it is happening; only when it is over can it become the subject of narration" (p. 164).

Narratives assume many forms, for example, in this study, stories were heard in interviews, they were written in a participant's journals and they were told about photographs and NICU memorabilia. Narrative researchers can gain insight into the ways that human beings understand and live their lives through stories. For example, in my own interviews with NICU mothers, I have noticed that all four participants described the NICU experience as a rollercoaster. They acknowledge that it there was always something to focus on, worry about and pray over, all the time. For the participants in this study, the rollercoaster represented not only their emotional and physical responses to the experience but also the way they experienced time. Time was noted to speed up with a sense of urgency at times and drag on at other times. It was reversed with decline and moved forward with progress. The pace and movement was always in flux as mother's waited for what was around the next bend. Sandelowski (1991) summed it up best, "A narrative framework affords nursing scholars a

special access to the human experience of time, order, and change, and it obligates us to listen to the human impulse to tell tales" (p.165).

### Uses and Limitations of Narrative Inquiry

The major value of a narrative approach is that it affords the opportunity to study personal life experiences and meaning. However, narrative inquiry is not useful for large numbers of nameless, faceless subjects (Riessman, 1993). The approach is very time and labor intensive. Narrative methods require a careful reading of the data for nuances of speech, the organizations of narrative elements, contextual features which are all complex conditions and states that describe experience and the social discourses that shaped the experience (Charon, 2006; Riessman 1993). It was for these reasons that the current study was limited to four participants.

### Recommendations for Future Research

Since the main intention at the beginning of this study was to inquire into mother's NICU experiences, I attempted to restrict the inquiry to the topic of the NICU experience. However, all four participants pointed out that the NICU experience encompassed much more than an NICU admission. The NICU experience for participant mother's began with their hopes, plans and goals for the first pregnancy, birth and baby and went beyond the NICU to include the mother's concerns for the baby's future.

As I look back on the study findings, I would have made several changes to the study. Instead of asking mother's to tell me the story of their NICU experience first, I would have asked for more detailed stories of their hopes and dreams for their first pregnancy, birth and baby. I would have followed up by

asking the participants to tell about their NICU experience and how that experience compromised their initial hopes and dreams, and finally I would have asked more about the mother's future concerns. I therefore, encourage other nurses interested in narrative inquiry to leave the line questioning somewhat open, so that participants have an opportunity to guide the studies direction.

I was not aware at the time of this inquiry, just how important these story types were for the participant mothers. It was in retrospect and only through collaboration with participants that the story types (enchantment, disenchantment and re-enchantment) became clearer.

While this study was in progress, Raelee emailed photographs of Owen to me on his one year birthday. The day that I received his photographs had been a particularly stressful day for me as I was trying to figure out how to balance the responsibilities of work and school; I was feeling frustrated with the additional responsibilities imposed on nurses in the healthcare setting like, computerized charting, meetings, etc., activities that often take us away from the patient's bedside. My nursing practice did not always shape up the way that I had imagined it would. At that moment, I realized that I too had been feeling a little disenchanted with healthcare. But upon seeing Owen's picture, I was re-enchanted with the complicating and demanding work of nursing, and I wondered, what other nurses stories would be shaped like. But that is a study for another day, for now I encourage readers to decide if the three story types described in this study: enchantment, disenchantment and re-enchantment have applicability to other circumstances and contexts in healthcare.

## Summary

I leave this study now to my nursing colleagues to determine the validity of my approach. I believe that the findings will reveal that I have taken risks as a novice narrative researcher and that I may have made some mistakes along the way as any novice will on their path to understanding. But I do encourage my nursing colleagues to identify mistakes, and to provide clarification of the narrative understandings identified here. "The quality of research often resides in how fruitful our mistakes are: that is, in whether they open up paths on which others can then make more progress than we have" (Gee, 2005, p. 9).

## APPENDIX A

### HUMAN SUBJECTS IN RESEARCH (IRB) APPLICATION AND LETTERS of AGREEMENT

#### I. Statement of Project Goals

The purpose of this qualitative research study using a narrative methodology is to seek descriptions (stories) of mothers' Neonatal Intensive Care Unit (NICU) experiences. There are three specific aims: (1) to better understand the stories told by mothers' who have had the experience of having had an infant in the NICU, (2) To explore moral problems and issues represented and constructed in the stories told by mothers, and (3) To contribute to improvements in clinical practice in the NICU.

Research based on studying whole persons in context and in time through narratives of their experience requires a major shift in perspective and approach. In order to examine notions of the good life, what is worth being and preserving for mothers, one must study the everyday ethical concerns and narratives of mothers who have experienced the NICU. The stories told by mothers can provide the necessary background for promoting understanding for everyday (moral) concerns and can help the healthcare practitioner to seek ways of enriching and transforming that experience for mothers. With that idea in mind, the current qualitative narrative research study will seek to address the following research questions:

1. What stories are told by mothers who have had the experience of having a baby in the neonatal intensive care unit (NICU)?
2. What stories do mothers' tell about shared artifacts collected from the NICU such as memorabilia, poetry, art, photographs, memory books, scrap books, journals?
3. What do the stories reveal about the mothers' search for meaning in the NICU experience?
4. What moral problems and issues are represented and constructed in the stories told by mothers.
5. How might mothers' stories help shape the practices of nurses and healthcare providers in ways respectful of the meanings, obstacle, contradictions, options, and possibilities that their stories disclose?
6. How might these findings promote dialogue among healthcare providers in order to preserve and extend responsiveness, care, comfort, safety, hope and opportunity for mothers and ill infants beyond the NICU?

#### II. Protocol

The following are the steps to be employed in the study:

1. Contact will be made with gatekeepers to identify and recruit interview participants following their discharge from the NICU. Participants must have been discharged from the NICU for a minimum of six weeks and no longer than six months to be included in the study.

2. Potential participants will be asked to complete a return postcard, indicating their interest in participating in the study and giving the researcher permission to contact them (**see appendix A**).
3. After receiving the postcard the researcher will contact potential participant both by phone to explain the purpose of the study and to invite their participation in the study (**see appendix B**).
4. Each participant will be given a packet containing the following information and forms: Return postcard, invitation letter to participate, consent form, consent information form, demographic questionnaire.
5. Interview one will be scheduled at a time convenient to the participant in the participants home or a mutually agreed upon location.
6. Prior to each interview, participants will be given a consent form information sheet (**see appendix C**) and asked to sign consent form (**see appendix D**) to participate and have interviews audio-taped.
7. Prior to each interview audio tapes will be labeled with date of interview, participant pseudonym, location of interview, and tape number.
8. Interview one will take place in a minimally structured manner, inviting participants to tell about their pregnancy and their experience while in the NICU. Participants will also be provided an opportunity to share artifacts from their NICU experience and invited to tell stories about the items they shared.
9. Interview two, may take place following a 15 minute break on the same day as the initial interview or on a later day as near to the initial interview as possible. Preferably, interview two will take place within two weeks of the initial interview. During interview two the participant will be asked for more stories about the topics that were raised in the initial interview.
10. Immediately following the first two interviews, the researcher will record process/debriefing/field notes.
11. Preliminary analysis of interview one and two will take place prior to interview three.
12. Interview three is always a separate interview with interview questions arising from the preliminary analysis of interview one and two.
13. Transcribe interview data and process noted verbatim.
14. Perform narrative analysis of interview data focusing on the following commonplaces or bedrocks of narrative: temporality, singularity, causality/contingency, intersubjectivity, ethicality.
15. Develop a written report on analysis

**a. Procedures:**

**Interview one:** A signed consent will be obtained prior to beginning the audio-taped interview. Interview question may go something like this: "I would like you to tell me the story of your NICU experience, any events and experiences that were important to you up until now. Start wherever you like. Please take the time that you need. I'll listen first, I won't interrupt, I'll take notes for after you are finished telling me about your

experiences' I'll tell you if we are running seriously out of time". You may share items that you collected during your NICU experience at whatever point you would like.

**Interview two:** A signed consent will be obtained prior to beginning the audio-taped interview. During interview two the interviewer will ask for more stories about topics that were raised in the initial narration, following the strict order in which they were raised by the participant and using the words of the participant in respect to topics. Topics may be missed out, but an earlier topic cannot be raised once a latter one has been addressed, the rationale for doing this is to maintain the gestalt of the individual being interviewed. The questions in this interview are strictly for more story, for instance, the second interview may include the following questions to return the participant to the narrative: Tell me more about X; Please describe the incident/experience of X in terms of time, place, situation, and participants; In the incident you spoke about, what was the sequence of events? What did you mean by X?

**Self-debriefing and field notes** will be written down or recorded for a period of 30-60 minutes following the first two interviews. These notes are material from the researcher's short-term memory that will be lost as the researcher leaves the interview location and does things that distract attention away from the interview.

**Interview three:** A signed consent will be obtained prior to the beginning audio-taped interview. Interview three is always a separate interview. To prepare for it the interviewer will have completed a preliminary analysis at least of the material gathered so far in interview one and two. On the basis of that preliminary data analysis and in light of the research purposes and theory, the interviewer will develop a set of questions which may include but will not be restricted to the type of narrative-pointed used in the first two interviews. Interview three is completely structured by questions arising from preliminary analysis of the material from the first two interviews and the interviewer's concerns which gives a strong directional flow to the interview. Here any question can be asked about topics not previously mentioned.

Interview data and process notes will be transcribed verbatim. Debriefing/field notes will be recorded on paper or tape. Analysis will be directed toward understanding each participant's experiences as perceived by the individual over time as a case, each case can then be compared within and between other cases.

Any artifacts shared during the interviews will be photocopied, photographed or videotaped and recorded for analysis along with the interview transcripts after obtaining consent to do so.



Following each interview a tape log (see appendix E) will be completed and an interview tracking form maintained in a locked file for safekeeping during the study. After five years, the recordings, list of interviewees and consent forms will be destroyed or returned to participants at their request.

**b. Number and age range of subjects**

There will be a minimum of four and a maximum of six participants in this study. Participants are limited due to the nature of narrative inquiry. Each participant will be interviewed two to three times each. The goal of narrative inquiry is not to generalize from single cases or small samples but on in-depth understanding within and between participants. Narrative inquiry requires information rich cases whose participation will illuminate the questions under study. All participants will be 18 years of age or older. The inclusion of children is not appropriate for this study.

**c. Subject population**

Participants in this study will be selected using purposeful sampling design strategy because they are "information rich" and illuminative of the NICU experience. Inclusion criteria include, first-time mothers, ages 18-45 that have experienced the premature birth of an infant requiring care in the NICU for a minimum of 2 weeks. At the time of the first interview the participants must have been discharged from the NICU for a minimum of 6 weeks but no more than 6 months. The infant must be living at the time of the interview. Exclusion criteria include the following: mothers less than 18 year of age, mothers of multiples, mothers of infants with congenital anomalies, mothers of infants that died or were transferred to another facility during their NICU course.

**d. Study site**

The participants will be recruited through gatekeepers (primary nurses or physicians) following discharge from a 55 bed level III Regional Perinatal Center in Florida. Narrative interview locations will vary to meet the needs of the participants.

**e. Measurement tools**

The research design for this study is qualitative. Methodology consists of narrative interviews/narrative inquiry. Narrative Interviews are semi-structured in-depth interviews designed to elicit stories from participants. There will not be specific questions written, but a guide will be designed to elicit narratives or stories from participants. Transcription, coding, and narrative analysis of individual interviews will be performed. Analysis will focus on the following commonplaces or bedrocks of narrative: temporality, singularity, causality/contingency, intersubjectivity and ethicality.

### **III. Benefits**

Subjects will receive no financial compensation or other credit for participation. A potential benefit of mothers' telling their stories is that it will contribute insights into the experiences of mothers as they perceive the NICU experience. The aim of this study is to contribute knowledge to nurses in order to improve and extend responsiveness, care, comfort, safety, hope and opportunity for mothers and ill infants requiring care in the NICU.

### **IV. Risks**

The interviews will focus on women's experiences with having had an infant requiring care in the NICU. All participants who volunteer will know the focus of the project and thus no one who does not wish to discuss her experiences will be contacted. Nonetheless, some women may experience discomforts in telling their story in that it exposes highly personal thoughts, feelings, knowledge, and experiences and makes them public for educational purposes. Participant will be made aware prior to the interview that they may voluntarily withdraw from the study at any time during the process without penalty. Potential participants may also be inconvenienced by the time required to participate in the study. However, as the interviewees are recruited on a volunteer basis, anyone who feels the time commitment is too great may choose not to volunteer.

The identity of all participants and the data collected will be kept confidential. When interviews are completed, they will be transcribed and filed using pseudonyms without inclusion of the participants' name or any other identifying markers and saved to disk. To ensure confidentiality, a master list matching pseudonyms to actual names will be stored in a locked file cabinet, and all information will be stored on password protected computer files or in a locked file cabinet at the researcher's office along with the signed consent forms. Only the dissertation committee will be able to see the original transcripts. The audiotapes will be returned to the participant or destroyed after a period of five years. Only information, with no personal information unless additional consent is obtained, will be presented at scientific meetings and published in journals. Should mothers feel that it is necessary to speak to a professional therapist/psychologist about issues causing them distress; the researcher will assist them in obtaining a list of service providers in the community. It will then be up to the subject to contact the therapist/psychologist for an appointment for evaluation (see appendix F).

### **V. Informed Consent**

Informed consent to participate will be obtained from each participant through presentation of a written document (see attached).

### **Enclosure Checklist**

  X             Original and one copy of proposal for college/division reviewer

(including page and complete narrative)

- X Original signatures from principal investigator and department chair (also advisor's signature, if applicable)
- X Letter from dissertation or thesis committee indicating approval of Research proposal
- NA Two copies of survey/research instruments
- X Permission letter from external agencies participating in the project
- X Consent form to be used (long or short)
- NA Oral presentation
- NA Assent Form
- X Cover letter or written instructions
- X Letter to parents
- NA List or description of organization to be contracted (school districts, hospitals, etc.)

## APPENDIX B

## RETURN POSTCARD

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Thank you for printing legibly!

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_

Zip Code \_\_\_\_\_

Telephone \_\_\_\_\_

Email \_\_\_\_\_



- I am interested in participating and agree to tell the story of my neonatal intensive care unit experience with the researcher, Angela Blackburn in two to three interview sessions lasting 1-3 hrs.
  - I am interested in sharing copies of items collected during my neonatal intensive care unit experience such as photographs, journals, poetry, art, memory books, scrap book memorabilia.
  - I give permission to be contacted about participating in interviews and a time for sharing items from my neonatal intensive care unit experience.
-

**APPENDIX C**  
**INVITATION LETTER to PARTICIPATE in INTERVIEWS**

Date:

To: Mrs. \_\_\_\_\_  
Address

Dear Ms. \_\_\_\_\_,

You are invited you to participate in a study titled, *Stories, Ethics and the Interpretation of Meaning: Bearing Witness to Mothers' of their Neonatal Intensive Care Unit Experience*. The purpose of this study is to explore mothers' stories of their neonatal intensive care hospital experiences. This study seeks to help nurses in understanding and providing improved care for mothers' and their infants while in the neonatal intensive care.

If you agree to participate in this study, you will be asked to take part in two to three interviews lasting approximately 1-3 hrs each with the student researcher, Angela Blackburn, which will be conducted either in your home or a place of your choice. The interviews will be arranged by Angela at a time that is convenient for you. The interview (s) will be audio-taped, with your consent. You will also be asked to share items that you collected while in the neonatal intensive care unit such as photographs, poetry, art, journals, memory books, scrap books, memorabilia, etc. and tell the story of the item(s).

Although, Angela Blackburn, is a neonatal nurse practitioner, she will not be working in that role during this study. Angela will be working in the role of student researcher. This study will assist Angela in completing her doctoral dissertation from the University of Southern Mississippi. Information from this study may be presented or published in academic journals or presented in academic or hospital settings with an audience of healthcare professionals. Your rights are taken very seriously, so confidentiality, will be maintained. As such, all materials have been reviewed and approved by the Institutional Review Board (IRB) at the University of Southern Mississippi (USM). Your participation is completely voluntary, and a consent form will be provided for you to sign.

Your first discussion will take place on Date. As a reminder, you will be telephoned on Date to confirm the meeting. If you are unable to participate, please contact Angela Blackburn at the number listed below. If you have any questions or want to further discuss this project, please feel free to contact Angela at (251) 867-8211 or via email at [acblackburn@bellsouth.net](mailto:acblackburn@bellsouth.net). Or you may contact Dr. Karen Saucier Lundy, professor and dissertation chair, The University of Southern Mississippi at (601) 266-6820.

Thank you,

Angela C. Blackburn

University of Southern Mississippi doctoral student

**APPENDIX D**  
**PROJECT/CONSENT INFORMATION SHEET for PARTICIPANTS**

**What am I being asked to do?**

- You are being asked to give your permission to take part in two to three tape recorded interviews with the student researcher, Angela Blackburn, in order to tell your story about your neonatal intensive care experience and to share items such as photographs, journals, poetry, art, memory books, scrap books, memorabilia, etc. that you collected during your neonatal intensive care course.

**Why have I been asked to take part in this study?**

- As the mother of a baby that required care in the neonatal intensive care, you are an expert in that experience. The researcher is interested in mothers who would like to tell their story in vivid, accurate and complete ways that describe exactly what the neonatal intensive care experience was like for them. She is interested in your thoughts, feelings, and behaviors, as well as situations, events, places, and people connected with your experience.

**How will the information and stories that I provide be used for this project?**

- The stories and information that I provide will contribute insights into the experiences of mothers as they perceive the neonatal intensive care experience. The aim of this project is to contribute knowledge to nurses in order to improve and extend responsiveness, care, comfort, safety, hope and opportunity for mothers and ill infants requiring care in the NICU.

**Will people know that I took part in this project?**

- Your name will never be revealed during any discussions, presentations, or exhibits. Still, there is a chance that someone may recognize you.

**What will I get out of sharing my story and my neonatal intensive care memorabilia in this study?**

- No monetary benefit will be provided. You will be contributing to nursing knowledge of mothers' experiences in the neonatal intensive care units which may lead to improved care and nurses responses to mothers needs when their baby is hospitalized.

**What are the risks associated with me providing this information to you?**

- There is minimal risk to you for providing this information; however, reliving some of the experiences may make you sad or uncomfortable.

**What if I decide that I do not want to continue the interviews?**

- You can withdraw from the study at any time by saying that you no longer want to participate in the interview. If you do withdraw from the study there will be no repercussions or penalty

**How will my information be kept confidential?**

- All interview tapes and shared items will be kept in a secured place by the researcher. No item shared with the researcher will be used for any financial gain. If you wish, I will send you a copy of any publication using the information that you provided. If you would like a copy, please write your name and address in the space provided below.

**Has the project been approved by the University of Southern Mississippi?**

- Yes. This project has been approved by the University of Southern Mississippi Institutional Review Board on Research Involving Human Subjects.

**Who can I contact if I have questions about this project?**

If you ever have any questions or concerns regarding this study or your rights as a research participant, please contact the student investigator, Angela Blackburn, at (251) 867-8211; or the dissertation chair Dr. Karen Saucier Lundy, Professor, The University of Southern Mississippi School of Nursing at (601) 266-4452; or The University of Southern Mississippi Human Subjects Protection Review Committee at (601) 266-6820.

**If you are willing to be interviewed by the researcher two to three times lasting 1-3 hrs each and if you are willing to share your Neonatal Intensive Care memorabilia, please read the following agreement very carefully. Please sign and date the form and I will give you a copy for your own records.**

**Agreement statement**

By signing this consent form, I agree to tell the story of my neonatal intensive care experience during two to three tape-recorded interviews with the researcher. I also agree to share items that I collected during my infants hospital stay (such as photographs, poetry, art, journals, memory books, etc) with the researcher and tell the story of the item. I also understand and agree that unless otherwise notified in writing, Angela Blackburn and the University of Southern Mississippi assumes that permission is granted to use the interview transcripts, and shared items collected during the hospital stay for project-related discussions, exhibits, or presentations.

Your signature \_\_\_\_\_

Researcher's signature \_\_\_\_\_

Date \_\_\_\_\_

Date \_\_\_\_\_

If you would like a copy of this dissertation or any publications created from the stories obtained in this study, please print your complete mailing address here:

Name \_\_\_\_\_

Address \_\_\_\_\_

City, State, Zip Code \_\_\_\_\_

## APPENDIX E

THE UNIVERSITY OF SOUTHERN MISSISSIPPI CONSENT FORM  
AUTHORIZATION TO PARTICIPATE IN RESEARCH PROJECT

Consent is hereby given to participate in the study titled: Stories, Ethics, and the Interpretation of Meaning: Bearing Witness to Mothers' Stories of Their Neonatal Intensive Care Unit Experience

- A. General Information
1. **Researcher/Organization:** Angela Chisum Blackburn/ University of Southern Mississippi
  2. **Purpose:** The purpose of this qualitative study is to seek descriptions (stories) of mothers NICU experiences.
  3. **Aims of the Study:** There are three specific aims: (1)To better understand the stories told by mothers' who have had the experience of having an infant in the Neonatal Intensive Care Unit (NICU), (2)To explore mothers' ethical concerns, and (3)To contribute to improvements in clinical practices in the NICU.
  4. **Description and Purpose of Procedures:** You will be interviewed by the researcher 2-3 times about your experience as a mother who has had a baby requiring care in the neonatal intensive unit. I am seeking vivid, accurate, and comprehensive portrayals of what the NICU experience was like for you; your thoughts, feelings, and behaviors, as well as situations, events, places, and people connected with your experience. The interviews will take place in the home of the participant or in another mutually agreed upon location. The interviews may last 1-3 hrs each. Interviews will be audio-recorded and transcribed verbatim. You will also be asked to share stories of artifacts that you collected during your NICU experience such as: photographs, memorabilia, journals, poetry, artwork, memory books, scrap books, etc. Artifacts presented by each participant may be photocopied, photographed or videotaped as a form of documentation by the researcher. Stories told about artifacts will also be audio or video-recorded.
  5. **Use of Results:** Your stories will be combined with the stories of other participants. Important themes and story types will be explored. The importance of stories in revealing important moral issues will be discussed. These issues will be later explored for their possible contribution to improvements in care given to infants and families in the NICU. The research findings will be published in this dissertation. Findings may also be published in professional journals or presented at conferences for educational purposes for healthcare professionals.



6. **Possible Risks:** All risks can not be predicted. However, you may experience discomforts in telling your story in that it exposes highly personal thoughts, feelings, knowledge, and experiences and makes them public for educational purposes. The University of Southern Mississippi has no mechanism to provide compensation for participants who may incur discomforts or injuries as a result of participating in research projects. However, efforts will be made to make available the facilities and professional skills at the University. Should you feel at any time that it is necessary for you to speak to a professional therapist/psychologist about issues that may be causing you distress, the researcher will assist you in obtaining information about therapist/psychologists who provide services in your community. It will then be up to the participant to contact the therapist/psychologist for an appointment for evaluation.
7. **Possible Benefits:** Potential benefits of telling your story is that it will contribute insights into the experiences of mothers as they perceive the NICU. The aim of this study is to contribute knowledge to nurses in order to improve and extend responsiveness, care, comfort, safety, hope and opportunity for mothers and ill infants requiring care in the NICU.
8. **Confidentiality:** You should be aware that information shared for this research is confidential. Interviews will be audio taped and transcribed and maintained along with documentation of shared artifacts. These items will be stored in a confidential locked file. Findings of the study will be used in the process of completing a Ph.D. degree, including a dissertation and any future publications for educational purposes. Your identity and any identifying information will remain known only to Angela Blackburn. The transcripts will remain with the researcher, locked in a secure file. At the end of the study transcripts will be released to participants or destroyed.
9. **Subject's Assurance:** Whereas no assurance can be made concerning results that may be obtained (since results from investigational studies cannot be predicted) the researcher will take every precaution consistent with the best scientific practice. Participation in this project is completely voluntary, and participants may withdraw from this study at any time without penalty, prejudice, or loss of benefits. Questions concerning the research should be directed to Angela Blackburn at 251-867-8211(H) or 251-363-5711 (C). You may also contact my dissertation chair Dr. Kay Lundy at (601) 266-4452. This project and this consent form have been reviewed by the Institutional Review Board, which ensures that research projects involving human subjects follow federal regulations. Any questions or concerns about rights as a research subject should be directed to the Chair of the Institutional Review Board, The University of Southern

Mississippi, 118 College Drive #5147, Hattiesburg, MS 39406-0001, (601) 266-6820. A copy of this form will be given to the participant.

10. **Signatures:** In conformance with the federal guideline, the signature of the participant must appear on all written consents documents. The University also requires that the date and the signature of the person explaining the study to the subject appear on the consent form.

Signature of Research Participant

Date

Phone number(s):

Email

Address:

Signature of Person Explaining the Study

Date

Phone number (s)

Email Address:



**APPENDIX G****REFERENCE LIST for SUPPORT GROUPS and COUNSELING**

**Sacred Heart Hospital Postpartum Depression Support Group**  
To register for this support group, please call (850) 416-1600.

**Postpartum Support International**  
<http://www.postpartum.net>  
Or Contact Jennifer Moyer at 850-936-7164

To obtain a list of Psychologist/Psychiatrist in your area  
Search <http://www.switchboard.com/>  
Enter your city, state  
You will find a list of local physicians/counselors including  
phone number, address and driving locations

## APPENDIX H

## LETTER of AGREEMENT USM SCHOOL of NURSING

**THE UNIVERSITY OF SOUTHERN MISSISSIPPI**  
*School of Nursing*

Office of the Director  
118 College Drive #5095  
Hattiesburg, MS 39406-0001  
601.266.5445  
[www.usm.edu/nursing/](http://www.usm.edu/nursing/)  
**The POWER to INSPIRE**

May 22, 2008

Betty Ann Morgan  
The University of Southern Mississippi  
Box 5147  
Hattiesburg, MS 39406-0001

Dear Ms. Morgan,

I am writing my support and permission for Angle Blackburn to conduct research involving human subjects for her dissertation project entitled "Stories, Ethics, and the Interpretation of Meaning: Bearing Witness to Mothers" Stories of the Neonatal Intensive Care Unit Experience." Angela is a doctoral student at The University of Southern Mississippi and is working under her chair Dr. Karen Lundy. Her research is being conducted at the Sacred Heart Hospital in Pensacola Florida.

Ms. Blackburn will be interviewing mothers, post discharge, who had infants admitted to the Neonatal Intensive Care Unit. Please let me know if you need any further information.

Sincerely,

Handwritten signature of Katherine E. Nugent, PhD, RN.

Katherine E Nugent, PhD, RN  
Professor & Director, School of Nursing  
Associate Dean, College of Health  
The University of Southern Mississippi

SCHOOL OF NURSING  
A TRADITION OF EXCELLENCE WITH

## APPENDIX I

## IRB APPROVAL LETTER: SACRED HEART HOSPITAL

**DATE:** May 21, 2008

**TO:** Angela Blackburn, RN, BSN  
**FROM:** Sacred Heart Clinical Investigation Review Board (CIRB)

**STUDY TITLE:** [89518-1] "Stories, Ethics, and the Interpretation of Meaning: Bearing Witness to Mothers' Stories of their Neonatal Intensive Care Unit Experience."  
**SUBMISSION:** Expedited review of new study  
**SUBMISSION TYPE:** Other

**ACTION:** APPROVED  
**APPROVAL DATE:** May 23, 2008  
**EXPIRATION DATE:** June 9, 2009  
**REVIEW TYPE:** Expedited Review

Thank you for your submission of Other materials for this research study. Sacred Heart Clinical Investigation Review Board (CIRB) has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a study design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This study has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the study and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the study via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the signed consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All SERIOUS and UNEXPECTED adverse events must be reported to this office. Please use the appropriate adverse event forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

Please report all NON-COMPLIANCE issues or COMPLAINTS regarding this study to this office.

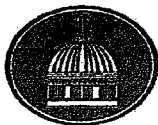
Please note that all research records must be retained for a minimum of three years.

Based on the risks, this project requires Continuing Review by this office on an annual basis. Please use the appropriate renewal forms for this procedure.

If you have any questions, please contact Ken Grissett at (850) 416-4279 or kgrissett@shhpens.org. Please include your study title and reference number in all correspondence with this office.

## APPENDIX J

## UNIVERSITY IRB APPROVAL LETTER


**THE UNIVERSITY OF SOUTHERN MISSISSIPPI**
**Institutional Review Board**

 118 College Drive #5147  
 Hattiesburg, MS 39406-0001  
 Tel: 601.266.6820  
 Fax: 601.266.5509  
 www.usm.edu/irb

**HUMAN SUBJECTS PROTECTION REVIEW COMMITTEE  
 NOTICE OF COMMITTEE ACTION**

The project has been reviewed by The University of Southern Mississippi Human Subjects Protection Review Committee in accordance with Federal Drug Administration regulations (21 CFR 26, 111), Department of Health and Human Services (45 CFR Part 46), and university guidelines to ensure adherence to the following criteria:

- The risks to subjects are minimized.
- The risks to subjects are reasonable in relation to the anticipated benefits.
- The selection of subjects is equitable.
- Informed consent is adequate and appropriately documented.
- Where appropriate, the research plan makes adequate provisions for monitoring the data collected to ensure the safety of the subjects.
- Where appropriate, there are adequate provisions to protect the privacy of subjects and to maintain the confidentiality of all data.
- Appropriate additional safeguards have been included to protect vulnerable subjects.
- Any unanticipated, serious, or continuing problems encountered regarding risks to subjects must be reported immediately, but not later than 10 days following the event. This should be reported to the IRB Office via the "Adverse Effect Report Form".
- If approved, the maximum period of approval is limited to twelve months. Projects that exceed this period must submit an application for renewal or continuation.

**PROTOCOL NUMBER: 28060202**
**PROJECT TITLE: Stories, Ethics, and the Interpretation of Meaning: Bearing Witness to Mothers' Stories of Their Neonatal Intensive Care Unit Experience**
**PROPOSED PROJECT DATES: 09/01/01 to 10/31/08**
**PROJECT TYPE: Dissertation or Thesis**
**PRINCIPAL INVESTIGATORS: Angela Chisum Blackburn**
**COLLEGE/DIVISION: College of Health**
**DEPARTMENT: Nursing**
**FUNDING AGENCY: N/A**
**HSPRC COMMITTEE ACTION: Expedited Review Approval**
**PERIOD OF APPROVAL: 06/12/08 to 06/11/09**

  
 \_\_\_\_\_  
 Lawrence A. Hosman, Ph.D.  
 HSPRC Chair

6-13-08  
 \_\_\_\_\_  
 Date

## APPENDIX K

## UNIVERSITY IRB REVIEW FORM

HUMAN SUBJECTS REVIEW FORM  
UNIVERSITY OF SOUTHERN MISSISSIPPI  
(SUBMIT THIS FORM IN DUPLICATE)

Protocol # 08116400  
(office use only)

Name Angela Chisum Blackburn Phone 251-867-3211

E-Mail Address acblackburn@hscsouth.net

Mailing Address 102 Douglas Lane Brewton, Alabama 36428  
(address to receive information regarding this application)

College/Division College of Health Dept Nursing

Department Box # 5095 Phone 601-286-6457

Proposed Project Dates: From September 2001 To October 2008  
(specify month, day and year of the beginning and ending dates of the project, not just data collection)

Title Stories, Ethics and the Interpretation of Meaning: Bearing Witness to Mothers' Stories of their Neonatal Intensive

Care Unit Experience \_\_\_\_\_

Funding Agencies or Research Sponsors N/A

Grant Number (when applicable) \_\_\_\_\_

\_\_\_\_\_  
New Project

X  
Dissertation or Thesis

\_\_\_\_\_  
Renewal or Continuation: Protocol # \_\_\_\_\_

\_\_\_\_\_  
Change in Previously Approved Project: Protocol # \_\_\_\_\_

Angela Chisum Blackburn 5/9/08  
Principal Investigator Date

Karenaucier Lundy 5/29/08  
Advisor Date

Karenaucier Lundy 5/29/08  
Department Chair Date

## RECOMMENDATION OF HSPRC MEMBER

\_\_\_\_\_  
Category I, Exempt under Subpart A, Section 46.101 ( ) ( ), 45CFR46.

X  
Category II, Expedited Review, Subpart A, Section 46.110 and Subparagraph ( ) . . .

\_\_\_\_\_  
Category III, Full Committee Review.

Dr. Nordin T. James 6/9/08  
HSPRC College/Division Member DATE

Laura G. Norman 6-13-08



## APPENDIX L

## PANEL of EXPERTS

Karen Saucier Lundy, Ph.D., R. N., FAAN.  
Professor, The University of Southern Mississippi  
School of Nursing

Bonnie Lee Harbaugh, Ph.D., R.N.  
Associate Professor, The University of Southern Mississippi  
School of Nursing

Sherry Hartman, Dr.P.H., R.N. Emeritus Professor,  
The University of Southern Mississippi  
School of Nursing

Susan Mayfield Johnson, Ph.D., MPH, CHES  
The University of Southern Mississippi

Sarah Steen Lauterbach, R.N., MN, MSPH, Ed.D., Professor  
Valdosta State University  
College of Nursing

Amy Chasteen Miller, Ph.D.  
Associate Professor of Sociology  
The University of Southern Mississippi

Rebekah E. Young, MPH, CHES  
Transcriber

Nancy Barksdale, MSN, ARNP, NNP-BC  
Neonatal Nurse Practitioner  
Pediatrix Medical Group  
Reviewer/Editor of the study manuscript

Paula Fulford, RN, ARNP  
Neonatal Nurse Practitioner  
Pediatrix Medical Group  
Review/Editor of the study manuscript

## APPENDIX M

## DEMOGRAPHIC QUESTIONNAIRE

Dear Participant,

Welcome to *Stories, Ethics and the Interpretation of Meaning: Bearing Witness to Mothers Stories of their NICU experience*. I appreciate your interest in this study and hope that you find it beneficial. Before we begin, I would like for you to complete this packet by signing a consent form and answering a few questions. If you have any questions or concerns please feel free to call Angela Blackburn (Investigator) at (251)-867-8211 or Dr. Kay Lundy (Dissertation Director) at (601) 266-4452. When you have completed this packet, please send it to me in the provided stamped envelope or drop it off at the Intensive Care Nursery at Sacred Heart Children's Hospital.

Thank you for your time.

Please answer the following questions about you as mother of infant.

1. Your date of birth \_\_\_\_\_ (day) \_\_\_\_\_ (month) \_\_\_\_\_ (year)
2. Ethnic Identification \_\_\_\_\_
3. Occupation \_\_\_\_\_
4. Household income (circle one)  
At or below \$20,000/\$30,000/\$40,000/\$50,000/\$60,000/  
over 70,000/prefer not to answer
5. Number of children in your household \_\_\_\_\_
6. Marital status (circle one) Married/Single/Divorced/Other \_\_\_\_\_
7. Did you keep a journal or diary while your infant was hospitalized? (circle one) Yes/No
8. Do you currently keep a journal or diary? (Circle one) Yes/No
9. After the birth of your child, did your child require care in the intensive care nursery or Neonatal Intensive Care Unit? (Circle one) Yes/No
10. If your child did receive care in the Neonatal Intensive Care Unit what was he/she treated for? \_\_\_\_\_

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Please answer the following questions about your baby's father.

1. Date of birth \_\_\_\_\_ (day) \_\_\_\_\_ (month) \_\_\_\_\_ (year)
2. Ethnic Identification \_\_\_\_\_
3. Occupation \_\_\_\_\_

If your infant was hospitalized, please answer the following questions.

1. Gender (circle one) Male/Female/Ambiguous
2. Date of birth \_\_\_\_\_ (day) \_\_\_\_\_ (month) \_\_\_\_\_ (year)
3. Birth order of child (circle one) 1<sup>st</sup> born/ 2<sup>nd</sup>/3<sup>rd</sup>/4<sup>th</sup>/5<sup>th</sup>/other
4. How many days was your infant in the NICU ? \_\_\_\_\_ weeks.
5. Does your baby have any current medical or health conditions (circle one)  
Yes/No  
If "yes", what is/are the medical and health conditions?

## APPENDIX N

### RESEARCH PURPOSE (RP)

The purpose of this qualitative study is to seek descriptions (stories) of mothers NICU experiences. There are three specific aims: (a) To generate stories of mothers' NICU experiences, (b) to describe the meaning in the stories, and (c) to illuminate the ethical concerns embedded in mothers' stories.

### CENTRAL RESEARCH QUESTIONS (CRQ)

These questions are *theoretical research questions* posed by the researcher. They are *not interview questions*.

**THEORY QUESTION 1:** What stories are told by mothers who have had the experience of having a baby in the intensive care nursery?

**THEORY QUESTION 2:** What do the stories reveal about the mothers' search for meaning?

**THEORY QUESTION 3:** What are the ethical concerns represented and constructed in mothers' stories?

**THEORY QUESTION 4:** How might mothers' stories be viewed to improve care providers understanding of what is most common, most taken-for-granted and what concerns mothers' most so that quality care can then be provided?

## APPENDIX O

### INTERVIEW QUESTIONS

The following statements/questions guided the interviews with participants

#### **INTERVIEW QUESTIONS FROM THEORY QUESTION 1: STORY**

I would like for you to tell me the story of your NICU experience, all the events and experiences that were important to you up until now. Start wherever you like. Please take the time that you need. I'll listen first, I won't interrupt, I may take some notes so that I can ask additional questions after you have finished telling me about your experiences. I will let you know you if the time that we arranged for the interview is running out.

#### **INTERVIEW #2: QUESTIONS ENCOURAGING CLARIFICATION AND ELABORATION**

Interview #2; clarified and ask for more story from interview #1 in the order that the participant brought it up. Examples included:

Tell me more about X; Please describe the incident/experience of X in terms of time, place, situation, and participants; In the incident that you spoke about, what was the sequence of events?; What happened first?; What happened next? ;Then what happened?; What finally happened?; What significance did the experience have at the time it was occurring?; What did it mean to you at the time?; What is the significance of the experience in your life now?; Can you give an example of X?; Any other things you remember happening?; Do you remember/recall anything else?; Can you give me ANY example of an occasion when?; Can you give me any MORE examples of similar events, incidents at that time/ of

that type?; Was there some particular CRUCIAL incident or situation or time that you can recall?

### **POTENTIAL RESEARCH QUESTION FOR INTERVIEW #3**

The potential research questions listed here were questions that helped to clarify the mother's search for meaning, moral concerns embedded in her story and her values and beliefs. Not all of these questions were asked. They were only used as a guide for the third interview.

#### **INTERVIEW QUESTIONS FROM THEORY QUESTION 2: MEANING**

Given what you have said about your experience while in the NICU and where you are today. How have you made sense of your situation?

#### **INTERVIEW QUESTIONS FROM THEORY QUESTIONS 3: MORAL ISSUE**

What was it like to have to make difficult decisions while in the NICU?

Could you tell me about a day in the NICU when you had to make a difficult decision?

What was that like for you?

Could you tell me about the people who supported you/or failed to support you with this difficult decision?

#### **INTERVIEW QUESTIONS FROM THEORY QUESTIONS 4: VALUES**

Are there certain characteristics that you valued in your care providers?

In what ways did care providers earn your trust?

Did you ever want different things than what the nurse provided?

How would you have liked the nurse to handle your situation?

How has your situation changed your values and beliefs?

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