To my wonderful children
Austin, Troy, Lauren, Noah, Adam

“Now I know there is no other love like a mother’s love for her child.”
R.J. Lange
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A premature birth is an unexpected event forcing parents to immediately make life altering decisions that will affect not only themselves, but entire families. Parents are often ill-prepared to face the foreign environment of the neonatal intensive care unit (NICU). When an infant experiences a complication, such as intraventricular hemorrhage (IVH), the situation becomes more complex. Infants often require elaborate medical support and ongoing rehabilitation upon discharge. Neonatal staff members frequently express concerns that families do not really understand the complexity of the situation. Therefore, the purpose of this study was to explore the process of becoming a mother to an infant who has experienced intraventricular hemorrhage (IVH) following preterm birth with the intent of understanding the meaning mothers attribute to IVH and how meaning is developed in order to construct a substantive theory that explains this complex process.

Twenty-one interviews were conducted in this grounded theory study. Grounded theory is an interpretative research method that focuses on understanding meaning of phenomena as they are perceived and experienced by participants. Open-ended, loosely structured interview questions allowed discovery of maternal perceptions
regarding the phenomena of IVH. Data were analyzed using dimensional analysis, a comparative analytic strategy designed specifically for use with narrative texts in grounded theory studies.

An explanatory model was developed that illustrates reframing motherhood within the context of preterm birth complicated by IVH. Under conditions of infant constitution, maternal attributes, and unexpected course, mothers discovered what it meant to be a mother of an infant with IVH. Gathering information, interpreting messages, and making sense were primary processes used. Mothers began to understand their lives and their babies' lives would be different than anticipated. Through this process, mothers acknowledged a new uncertain life trajectory and developed the belief that they had power to influence the situation.

The findings of this research can be used by providers to understand how mothers develop their beliefs about neonatal IVH. This will allow development of family-centered treatment plans that incorporate maternal beliefs. This research adds to the body of neonatal research as there are no studies addressing maternal understanding of neonatal IVH.
CHAPTER 1
OVERVIEW

Introduction

Pregnancy and childbirth is a complex, multidimensional life event. The birth of a child is not only a biological event; it is a social phenomenon that is steeped in cultural traditions and expectations. It is often a time of celebration and joy for families. However, the anticipated joy and celebration are exchanged for fear and uncertainty when birth occurs too soon. When a birth occurs prematurely, the sudden transition into parenthood can be a time of tremendous stress and heartache. Traditions and expectations are relinquished to hospital routines and medical jargon. A preterm birth may occur for a variety of reasons related to the health of the mother or infant. It may occur amidst ongoing pregnancy complications or abruptly without warning. However, it always results in a pregnancy that ended too soon and a baby born too early. The implications for the mothers and babies are immediate and far-reaching. The infant may suffer severe complications or even death. Mothers are recovering from the physical and psychological strain of childbirth while entering an unexpected and uncertain motherhood.

The purpose of this study was to explore the process of becoming a mother to an infant who has experienced an intraventricular hemorrhage (IVH) following preterm birth with the intent of (1) understanding the meaning mothers attribute to IVH and (2) how meaning is developed. There is often concern among neonatal intensive care unit (NICU) staff that mothers do not understand the long-term implications of this diagnosis. However, IVH is a diagnosis of great outcome uncertainty. Children may have no discernible deficits ranging to severe disability. It is crucial to understand the maternal
perspective of this event in order to provide meaningful support and guidance throughout the neonatal intensive care unit stay and beyond.

**Background of Problem**

A preterm birth is defined by the World Health Organization (WHO) as delivery of an infant prior to 37 weeks gestation (1992). However, there is wide variation in life expectancy and developmental outcomes of preterm infants born between 22 through 36 weeks gestation. Due to the inverse relationship between gestational age and morbidity and mortality, infants at lower gestational ages are at greater risk of both morbidity and mortality. Very premature infants (VPT), those born prior to 32 weeks, are at significantly higher risk; whereas, the most vulnerable are those infants born extremely premature at less than 28 weeks gestation.

**Preterm Birth Incidence**

Due to lack of registration systems and home births there is not a global measure of preterm births, but using analyses for multiple individual countries Beck and associates (2010) estimate in 2005 that 9.6% of all births were preterm. This translates to 12.9 million preterm infants born globally. Some scholars believe this is an underestimate of the actual preterm birth rate. Of the 12.9 preterm births, 10.9 million occurred in Africa and Asia (Beck et al.). Preterm birth rates in Africa are estimated at 11.9% of all births and the U.S. follows closely with a preterm birth rate of 10.65% (Beck et al.). This is below the Institute of Medicine (IOM) (2006) report that declared 12.5% of all births in the U.S. occurred prior to 37 weeks gestation. The preterm birth rate for infants <34 weeks is estimated at 3.5% of births (Hamilton, Martin, & Ventura, 2011). The IOM reported the cost of premature birth to be $26.2 billion dollars in the U.S.; however, this figure does not include cost beyond early childhood or caregiver
expenses. The impact of preterm birth on families and communities is immeasurable and extends far beyond financial costs.

**Preterm Birth Causes**

Despite technological advances, preterm births continue to be the second leading cause of infant mortality in the U.S. (Centers for Disease Control and Prevention, 2007). The reasons for preterm birth remain largely unknown, but are thought to be related to a complex interaction of physical factors strongly influenced by sociocultural ecology. Reported risk factors often include maternal race, medical history, and behaviors such as smoking, illicit drugs, alcohol, stress, lack of prenatal care, and long working hours (March of Dimes Foundation, 2011). Discussion of individual risk factors isolated from their sociocultural context may lead to an overly simplified understanding of these complex interactions and causation being placed with the mother. In over 50% of preterm births, the etiology is not identified (Masset et al., 2003).

**Neonatal Intensive Care**

In developed countries, preterm infants are often cared for in a hospital with a specialized neonatal intensive care unit in which technology is abundant. The preterm infant is often small and appears frail. This appearance may be further exacerbated by the large life-sustaining equipment that surrounds and is connected to the vulnerable infant. Neonatal units are typically open rooms with numerous bed spaces allowing visibility of many infants and their equipment. The environment can be noisy as alarms signal potential trouble. This is the setting in which parents are introduced to their new preterm babies for the first time. When life-sustaining measures are instituted, the abrupt transition into parenthood occurs in a technology-laden environment where parents are often asked to make a myriad of decisions for which they may be ill-
prepared. The complexity of the decisions parents will have to make increases dramatically if the gestational age of the baby is less than 26 weeks. Many medical professionals consider this the gray zone of viability and quality of life (Harrison, 2008). The National Institute of Child Health and Human Development Neonatal Research Network (2010) report a 25% mortality rate for infants born at 25 weeks gestation and a 95% mortality rate among infants born at 22 weeks gestation. In 2002, it is estimated that over 29,000 infants were born in this gray zone period (Savage & Kavanaugh, 2004). The U.S. Department of Health and Human Services reported in the National Vital Statistics Report that 1.97% of the 4,000,279 births in 2010 were prior to 32 weeks gestation (Hamilton, Martin, & Ventura, 2011).

**Ethical Implications**

In the U.S., it is common for these infants to be resuscitated at 22 weeks gestation and then decisions are made by providers and/or parents regarding continuation or withdrawal of support (Harrison, 2008; Fox, Platt, White, & Hulac, 2005). Delbeke (2009) referred to this as the start and reevaluate approach which she defends as the only ethical and legally justifiable approach. There are vast implications of this type of approach for families and society. It has been suggested that parents blame themselves for their child's death when treatment is withdrawn; however, if treatment is not initiated then the underlying problem is felt to be the cause (Baergen, 2006). Harrison (2008) argues that parents are the least informed participants in delivery rooms and the NICU. They do not understand the long-term impact of treating a baby “in the gray zone” and do not feel empowered to refuse treatment (Harrison, p. 329). It has also been suggested that the overwhelming coverage in the media regarding
“miracle babies” has left premature infants who do not survive or survive with disability as a “hidden dimension of our society” (Layne, 2000, p. 367 & 368).

**Parental Effects**

Repercussions of preterm birth are often discussed within the context of the physical and intellectual outcomes of the individual child affected; however, there are vast repercussions for parents as well. The likely psychological impact of preterm birth on parents has been recognized for many years. In the 1960s, Caplan and associates studied 30 families who had experienced a preterm birth and found the experience constituted an emotional crisis (Miles & Holditch-Davis, 1997). The experience has been described as an emotional roller coaster through an unfamiliar environment (Layne, 2000; Dockerty & Dockerty, 2006). Ricciardelli (2010) describes her preterm birth experience in her “unintentional ethnography” as an “emotional trauma” shaped by medical opinions, religious beliefs, and parenting choices (p. 1-2).

Parents face considerable stress in the foreign environment of the NICU after the birth of a premature infant. They describe the NICU as an overwhelming and alien environment in which there are no landmarks to help them negotiate (Gavey, 2007; Hall, 2005; Jackson, Ternestedt, & Schollin, 2003). Mothers, in particular, experience grief over the loss of the normal pregnancy and their child’s health status (Golish & Powell, 2003). Emotions such as disbelief, anxiety, sadness, anger, jealousy, guilt, self-blame, and shock regarding the birth conflict with the overall joy about the baby (Golish & Powell, Hall).

**Neonatal Morbidity and Mortality**

The first specialized unit for neonates was developed in the U.S. at Yale-New Haven Hospital in 1960 (National Institutes of Health, 1992). Since this time significant
improvements in mortality have occurred, especially during the past two decades with aggressive interventions such as the routine use of high-frequency oscillatory ventilation, inhaled nitrous oxide, surfactant, indomethacin, and antenatal corticosteroids (Patra, Wilson-Costello, Taylor, & Mercuri-Minich, 2006). However, preterm birth remains the leading cause of neonatal mortality with over 60% of deaths occurring after VPT birth (Callaghan et al., 2006; Mathews & MacDorman, 2008). Although these statistics are bleak, 90% of infants born in the U.S. weighing more than 1000 grams survive (Meadow, Lee, Lin, & Lantos, 2004), resulting in an increase in morbidities and long-term disabilities (Savage & Kavanaugh, 2004). These infants remain at significantly higher risk of neurodevelopmental compromise, respiratory disease, sensory disturbances, gastrointestinal disease, and vulnerable immune systems (Institute of Medicine, 2006). Preterm births account for 20% of childhood mental retardation, 33% of childhood visual disturbance, and 50% of cerebral palsy (Spong, 2007).

**Intraventricular hemorrhage**

Neonatal intraventricular hemorrhage is a major source of morbidity that affects infants born extremely premature that has continued despite improvements in neonatal care (Baron et al., 2009; Roland & Hill, 2003). Intraventricular hemorrhage is defined as a hemorrhage that occurs within the vascular germinal matrix of the ventricular system (Roland & Hill). This vascular tissue typically involutes at 32-34 weeks of gestational age (Huang & Castillo, 2008). Therefore, infants born prior to the involution are at increased risk for hemorrhage within this area. The severity of the hemorrhage is most commonly determined by a grading system first reported by Papile and associates in 1978. Hemorrhages are categorized in grades I-IV: grade I hemorrhage is confined to
the subependymal germinal matrix, grade II hemorrhage is within the ventricle without ventricular dilation, grade III hemorrhage is within the ventricle with ventricular dilation, and grade IV hemorrhage involves the parenchyma (Greenberg, 2005). Grade I-II are usually labeled mild and grade III-IV are considered severe (Vohr & Ment, 1996; Tortorolo, Luciano, Papacci, & Tonelli, 1999 Ballabh, 2010).

**Intraventricular hemorrhage incidence**

Reported incidence rates of this type of hemorrhage vary dramatically. In 1984, Hawgood, Spong, and Yu reported the overall incidence of IVH in infants weighing less than 1500 grams as 46%. In 1989, Philip, Allan, Tito, and Wheeler reported a decline in periventricular-intraventricular hemorrhage in premature infants less than 34 weeks gestational age from 34-39% in 1980-1981 to 19-25% in 1986-1987. Paneth and associates (1993) reported the overall incidence of IVH in infants weighing less than 2,000 grams from 1984-1987 as 24.6%. The incidence of IVH in infants born less than 28 weeks gestation has been reported to be three times higher than infants born over 28 weeks gestation (Papile, 2002). Vassilyadi and associates (2009) reported the estimated overall incidence of IVH in infants born earlier than 32 weeks gestation is 10 to 20% and increases to between 24 and 50% for those weighing less than 1500 grams.

**Intraventricular hemorrhage implications**

Research has yielded inconsistent results in regards to the outcomes of these extremely premature infants (Savage & Kavanaugh, 2004; Behrman & Butler, 2007). However, it has been suggested that IVH is a significant indicator of long-term neurodevelopmental outcomes in premature infants (Boyce, Smith, & Cato, 1999; Behrman & Butler; Baron, Ahronovich, Erickson, Larson, & Litman., 2009). In 2006, Patra and associates reported that even mild grades (I&II) of IVH resulted in
significantly lower scores on the Bayley Scales of Infant Development and 2.6 times higher incidence of major neurologic impairment. D’Angio and associates (2002) reported an odds ratio of 4.6 for mental retardation in the presence of IVH and an odds ratio of 65.8 for mental retardation if there was associated parenchymal involvement. Brouwer and associates (2008) reported that infants with grade IV IVH had a 48.7% incidence of cerebral palsy. Severity of IVH was also found to have a direct correlation on functional status such that those with higher grades of IVH had poorer functional status (Vassilyadi et al., 2009).

Communication

While the evidence is strong that IVH will most likely cause some neurodevelopmental delays, the extent of resulting disability remains uncertain and hard to predict, making it difficult for neonatal physicians and nurses to provide parents with information regarding likely long-term outcomes. In an attempt to help parents understand potential for survival and associated long-term prognosis, practitioners provide information that is “neutral and objective” (Payot, Gendron, Lefebvre, & Douct, 2007, p. 1492). NICU staff members have expressed concerns as to whether parents really understand the information that is provided; whereas, parents have expressed a need to receive information that is more than clinical facts (Alderson, Hawthorne, & Killen, 2006; Payot et al).

Intraventricular hemorrhage occurs within the first 72 hours of life in greater than 90% of cases (Greenburg, 2005). During this time, the mother continues to recover from the physical and psychological aspects of childbirth. She may also be given information regarding the diagnosis of IVH. Statistics of potential risks and likely outcomes are offered to the mother by NICU staff in the hope that objective data will
help increase her understanding and assist her with decision making. However, she may not be capable of processing these numbers in any meaningful way as the situation is far too complex to be explained by statistical figures.

Communication regarding a diagnosis is a process in which both parties participate. Parents use information to construct meaning about the diagnosis and subsequent illness in terms of their socio-cultural beliefs and experiences (Abrams & Goodman, 1998). The meaning cannot simply be given to the parents, and statistics are not enough to help them formulate an understanding of the diagnosis. Payot and associates (2007) describe a “shared space” that can be used to explore the diagnosis meaning in terms of the mothers’ expectations, values, and beliefs. Others have suggested that providers invite negotiation as a means of jointly creating the meaning of a diagnosis (Abrams & Goodman).

**Maternal caregiving**

All family members are affected by the diagnosis of neonatal IVH. However, if the infant survives, in most cases he/she will eventually be discharged home from the hospital into the care of the mother who will have to negotiate between the roles of mother and caregiver. Mothers may feel insecure and ill-prepared to care for their infants (Jackson et al., 2003). The roles of caregiving and mothering are likely to be so enmeshed that mothers may not recognize the difference or associated stress. Jackson and associates found that mothers may assume roles similar to the NICU staff in which they constantly monitor the baby. This may result in maternal stress and fatigue. The entire family unit is likely to be affected by the demands of maternal caregiving.
**Purpose of the Study**

The magnitude and lack of examination of this problem demonstrates a critical need for research exploring maternal awareness and perceptions related to the potential implications of neonatal intraventricular hemorrhage. Therefore, the purpose of this study was (1) to explore the process of becoming a mother to an infant who has experienced an intraventricular hemorrhage (IVH) following preterm birth (2) to understand the meaning mothers attribute to IVH and how meaning is developed, and (3) to construct a substantive theory that explains this complex process.

**Research Questions**

- What are maternal beliefs related to the cause, course, cure, and consequences of neonatal IVH?
- How are beliefs about IVH constructed within the preterm birth experience?
- How does the combination of preterm birth and neonatal IVH affect motherhood?

**Definition of Terms**

- Extremely low birth weight - infants weighing less than 1000 grams at birth (Merenstein, 2005)
- Extremely preterm birth - infant born less than 28 weeks gestation (Howson, Kinney, & Lawn, 2012)
- Intraventricular hemorrhage - bleeding that occurs within the vascular germinal matrix of the ventricular system (Roland & Hill, 2003)
- Late preterm birth - delivery of an infant between 34 and 37 gestational weeks (Howson, Kinney, & Lawn, 2012)
- Mild intraventricular hemorrhage - grade I or II intraventricular hemorrhage: grade I bleeding is confined to the subependymal germinal matrix, grade II bleeding is within the ventricle without ventricular dilation (Greenburg, 2005)
- Moderate preterm birth - delivery of an infant between 32 and 37 weeks gestation (Howson, Kinney, & Lawn, 2012)
• Preterm birth - delivery of an infant prior to 37 weeks gestational age (World Health Organization, 1992)

• Severe intraventricular hemorrhage - grade III or IV intraventricular hemorrhage: grade III bleeding is within the ventricle with ventricular dilation, and grade IV bleeding involves the parenchyma (Greenburg, 2005)

• Very low birth weight - infants weighing less than 1500 grams at birth (Merenstein, 2005)

• Very preterm birth - infant born between 28 and 32 weeks gestation (World Health Organization, 1992)

Significance of the Research

Estimates of the prevalence of IVH in preterm infants vary widely. According to the Handbook of Neurosurgery, “the reported incidence of IVH varies from 30-90% with a realistic incidence reported as 40-45%” (Greenburg, 2005). Infants who experience IVH are at increased risk for significant developmental delays, cerebral palsy, and mental retardation. IVH is considered to be the most powerful predictor of cerebral palsy and cognitive deficits (Laptook et al., 2005). Volpe (1998) reported that 30-40% of infants with severe IVH had spastic motor deficits and cognitive deficits. As the survival of extremely premature infants continues to increase, the subsequent neurological morbidity also increases (Baron et al., 2009). Many of these infants will require long-term care and rehabilitation. The mothers of these infants must negotiate between the roles of mother and caregiver. By understanding the perceived implications of the diagnosis, health care providers can better assist mothers in learning how to use the health care system and potential resources, manage the complex medical care of the infant, coordinate the interdisciplinary team, provide education, establish a family centered plan of care, and set goals with the family. Subsequently, interventions
designed to meet the needs of the mother can be developed from the maternal perspective.

Although studies provide insight into the experience of parenting a preterm infant, there is little understanding concerning how parents perceive complications of IVH that may follow preterm birth. It is well established that preterm birth is highly stressful and can even be traumatic for parents. The accepted WHO definition of preterm birth simply relates to the number of weeks of gestation. In the NICU, preterm births are perceived in terms of potential mortality and morbidity that may result from early delivery and available life-sustaining measures. However, the meaning of preterm birth and subsequent complications is constructed through multidimensional social and cultural beliefs and expectations related to pregnancy and birth. Often research focuses on how decisions are made; however, the full agency of mothers can only be understood by acknowledging the importance of constructing meaning (Layne, 1996). Understanding the maternal perceptions of IVH can lead to improvements in family-centered care throughout the NICU experience, as well as in the long-term care of families who may continue to contend with the lasting implications. Due to a significant probability of long-term consequences for the infant, healthcare providers need to have an awareness of how mothers react to learning about these complications and how mothers are integrating the diagnosis into their belief system.

Summary

This chapter provided an introduction and background information pertinent to the problem of neonatal IVH. The purpose of the study was described and the research questions were identified. In the remainder of the chapter, definitions of terms specific to neonates were provided. The significance and magnitude of the problem was also
explained. The following chapter is the preliminary literature review conducted to provide an overview of the context of preterm birth.
CHAPTER 2
LITERATURE REVIEW

The purpose of this chapter is to provide the context in which preterm birth occurs and synthesize the literature related to the preterm birth experience and neonatal IVH. In constructivist grounded theory, an initial literature review is conducted to develop an understanding of salient concepts related to the problem and identify gaps (Charmaz, 2006). As analysis occurs, the literature is revisited in order to compare and contrast current concepts and findings with previous studies.

An extensive review of multidisciplinary literature was performed using MEDLINE, CINAHL, Blackwell Synergy, PsycLit, Science Direct, Wiley Science, Ovid, and Ebscohost for the years 1990-2011 related to maternal perceptions or meaning of neonatal IVH and subsequent implications. There was no literature found in any discipline that expressly addressed this topic. The search was then broadened. Relevant search terms included NICU, preterm birth, premature birth, preterm labor, parental experience, neonatal IVH, experience of premature birth and hospitalization, maternal well-being after premature birth, attachment and bonding in the NICU, staff (medical and nursing)-family interaction, illness meaning, and pregnancy beliefs. These categories are intended to overlap in order to develop a sense of the context in which the meaning of neonatal IVH is constructed. Therefore, this literature review describes dominant pregnancy socio-cultural beliefs within the U.S., preterm labor and birth, NICU experience, maternal well-being, provider-family communication, and maternal explanatory models. It is important to recognize that all of the studies regarding NICU experiences were performed outside the U.S. Many countries have policies that do not allow the resuscitation of infants at the lower limits of viability. Mothers in the U.S. may
experience the same type of emotions; however, their experience will most likely differ due to the extreme life sustaining measures that are employed in infants born extremely premature.

Dominant Pregnancy Socio-Cultural Beliefs

Pregnancy and childbirth are complex, multidimensional, inter-related life events. It is a universal biological event that always occurs within a given social structure and is understood through culture. Brigitte Jordan describes childbirth as “an intimate and complex transaction whose topic is physiological and whose language is cultural” (Jordan, 1993, p. 3). Culture is being defined broadly as “ways of knowing” (Moerman, 2002, p. 72) and specifically regarding “beliefs, values, practices, and traditions of behavior” (Wiley & Allen, 2009, p. 4). Although the focus of this section is on pregnancy and birth within the U.S., it is well recognized that political and geographic borders are not an accurate predictor of cultural beliefs. Nations are typically constructed of diverse groups of people. The population of the U.S. is made up of a wide range of people who maintain specific cultural traditions that are practiced within an “American” social structure. Culture is an evolving phenomenon. As people interact with members of other cultural groups, as social structures evolve, and as ecology changes, beliefs and practices are modified accordingly. The biologic or physiologic aspects of human pregnancy and birth have relatively little variation; however, there is tremendous variation in socially, morally, and culturally appropriate ways to conduct oneself during these life events. Examples of expected behaviors may include dietary restrictions, participation in prenatal care, and activity avoidance. The interaction of these dimensions with biology generates the birth experience.
In the U.S., pregnancy and birth have become increasingly medicalized over the last century. Biomedicine now dominates this life event. Women are expected by obstetricians and other members of society to fully participate in prenatal care by following prescribed recommendations such as dietary restrictions and prenatal testing (Strong, 2000). Their pregnancies should culminate in being delivered by a healthcare provider, usually a physician, within a hospital, in a specifically designed bed, and surrounded by technology in order to keep themselves and their babies safe. Less than 1% of deliveries in the U.S. currently occur outside of a hospital (MacDorman, Menacker, & Declercq, 2010).

In order to fully understand this current biomedical dominance, the history of this emergence must be acknowledged. Robbie Davis-Floyd (2003) suggests the roots of these beliefs can be traced back to the 17th century, when Descartes proposed the mind body duality. The body came to be viewed as a machine. Man became viewed as the ideal machine; whereas, a woman’s body was viewed as defective. Due to this view, birth was regarded as inherently dangerous requiring manipulation (Davis-Floyd). A society’s birthing system is designed to conform to conceptualizations about birth (Jordan, 1993) so this view resulted in a replacement of births attended by midwives and female family members with male physicians complemented by tools to “improve” the birth process. The perceptions of inherent dangers and technological improvements associated with pregnancy and birth have been further accentuated by the remarkable declines in maternal and infant mortality. However, it is an oversimplification to suggest a unidirectional correlation between an increase in the usage of technology and reduced mortality.
As pregnancy and birth have increasingly become regarded as a medical event that requires treatment, the natural aspects of women’s bodies’ ability to be pregnant and deliver without complication have been diminished. Smith and Condit (2000) reviewed the pictorial depiction of women contained in Williams Obstetrics, a leading obstetrical textbook, during the past century. They found that 87% of the pictures in a textbook about obstetrics were not of women but of tools and children. Of the remaining 13%, less than 1% of the pictures of women showed them in their entirety. This resulted in the pictures overwhelmingly depicting women as body parts. There were no pictures of women in a healthy state of pregnancy after the 1942 edition (Smith & Condit). Pictures that demonstrated an entire woman’s body during pregnancy were only used to illustrate a pregnancy complication and were typically minority women. Although this is far from a complete picture of how physicians are socialized in the specialty of obstetrics, it implies that emphasis has been placed on technology and women have been reduced to the sum of their parts which precludes efforts to provide holistic care.

The biomedical social structure that dominates pregnancy and birth is essential to understand because it is within this structure that biological aspects of pregnancy occur and cultural beliefs are practiced. When cultural beliefs are incongruent with biomedical beliefs, resulting actions of mothers are often portrayed as noncompliance and/or ignorance. Prenatal care has become a major focus of so called “noncompliance”. Prenatal care is the biomedical cornerstone in regards to ensuring a healthy pregnancy and delivery; although, there is relatively little evidence to support such a claim (Villar et al., 1991; Fiscella, 1995; Strong, 2000; Klerman et al., 2001). When guidelines of the
American Congress of Obstetrics and Gynecology are followed, women in the U.S. have approximately thirteen prenatal visits during a healthy forty week gestation pregnancy (AAP/ACOG, 2007). If a problem is identified, this number may increase dramatically. Yet according to The World FactBook, a publication of the Central Intelligence Agency, 46 countries reported a lower incidence of infant mortality in 2010 than the United States. Reported statistics of infant mortality have inherent flaws and rates cannot be attributed to any one cause; however, it is notable that infant mortality remains significantly higher in the U.S. than in countries offering far fewer healthcare services.

The utilization of prenatal care services varies greatly among women in the U.S.; however, most women receive some level of care prior to delivery. Humbert and Roberts (2009) attempted to understand the use of maternal and child healthcare services. In the study, women reported that they often felt the health recommendations were difficult to follow and irrelevant or incongruent with their own cultural practices. The women also felt they were treated poorly by staff during the visits. Their social networks, especially other women in their family, were their source of information. When the mothers deviated from the prescribed regime, it was due to a desire to help themselves or their child. This study highlights that there are often structural and cultural reasons mothers do not adhere to biomedical advice, but they are choosing behaviors they believe to be most beneficial to themselves and their children.

Although there are diverse cultural beliefs regarding pregnancy and birth in the U.S., women enculturated in America are living in a society that values technology and control (Davis-Floyd, 2003). Technology has become viewed as a powerful means to
control and separate human beings from nature. Therefore, a model of pregnancy care that is technologically laden in order to control and improve biological processes is congruent with general societal values. Over the last several decades, women have generally reported increased satisfaction with their birth experiences (Davis-Floyd; Jordan, 1993). One explanation may be the cultural expectation of “technobirth” through formal childbirth education that has been integrated into the medical system (Jordan, p. 144). Biomedical knowledge has been socially accepted as authoritative while other ways of knowing, such as maternal experience, have been diminished thus further driving women away from historical sources of knowledge. Understanding the power of authoritative knowledge is important because it is created and perpetuated not for its scientific accuracy but because it is socially viewed as being legitimate and worthy of action (Sargent & Bascope, 1993). As the knowledge is reproduced and acted upon, it is reinforced further creating the cycle of legitimizing one type of knowledge while diminishing another. The possessors of authoritative knowledge are viewed as powerful while those possessing other forms of knowledge are devalued.

Cultural beliefs are often so engrained into a societal structure that it may be difficult for an individual to recognize their own beliefs as anything other than absolute. In the U.S., technology and control are highly valued concepts. Linda Layne (2000) describes this as a belief in linear progress in which technology will continue to progress beyond current limitations. These concepts are embodied within the biomedical model which dominates beliefs regarding health, illness, and disease.

Beliefs about pregnancy and birth are also strongly influenced by the biomedical model that constructs these life events as inherently risky. This risk assessment
requires that pregnancy and birth be managed by those with authoritative knowledge in an effort to mitigate risk. These individuals are healthcare providers, most frequently physicians, socialized within the biomedical model. Regimens are prescribed for the pregnant woman to follow. Participation becomes a “moral obligation” because these actions are required to keep the woman and her baby safe (Jordan, 1993, p. 122). Although power and knowledge remains in the domain of biomedicine, the responsibility to produce and deliver a healthy infant remains solely with the individual woman. After 40 weeks of close medical management, the woman is expected to come to the hospital for the appropriate technologically-assisted delivery of her infant. This construction of pregnancy and birth provokes ethical concerns related to the agency of women, the power of authoritative knowledge, and individual responsibility.

**Preterm Labor and Birth**

The causes of preterm birth are believed to be a complex interaction of biological, social, and ecological factors; although, these factors remain poorly understood (Behrman & Butler, 2007). Risk factors associated with preterm labor such as maternal infection, smoking, spontaneous rupture of membranes, and maternal eclampsia are well recognized in biomedicine. However, the implications of social issues such as stress, poverty, food scarcity, and violence on preterm birth are not well understood. In 2007, the IOM reported there had been a 30% increase in preterm births since 1981 with African Americans being disproportionately affected. At 17.8% of all deliveries being premature, they have the highest rates of all ethnic groups in the U.S. (Behrman & Butler). Although some have suggested a possible genetic explanation for this, foreign born women of African American descent had preterm birth rates of 13.9% compared to U.S. born African American women whose preterm birth rates were 18.2%
(Behrman & Butler). Similarly, Mexican immigrants who lived in the U.S. longer than five years had higher preterm birth rates than Mexican immigrants living in the U.S. less than five years (Guendelman, English, & Chavez, 1995).

The incidence of very preterm birth in England also rose significantly between 1994 and 2004 (Smith, Draper, Manketelow, Dorling, & Field, 2007). Smith and associates compared women who were in the highest deprivation decile to women in the least deprived decile and found that the deprived women were more than twice as likely to deliver a preterm infant. In Northern Ireland, neonatal intensive care admissions were found to be 19% higher in deprived residential areas (Jenkins, McCall, Gardner, Casson, Dolk, 2009). These studies demonstrate an increased likelihood that women experiencing economic disparity will deliver preterm and/or deliver an infant who requires neonatal intensive care; however, there remains significant ambiguity regarding how socioeconomic status affects preterm delivery. Kramer and associates (2001) have hypothesized a causal pathway by which low socioeconomic status is linked to preterm birth through biological and social mediating factors; however, this hypothesis has not been tested.

Linda Layne (1996) published a first person narrative about “knowledge making” as she describes her experience with preterm delivery and the subsequent weeks spent in the NICU with her son. She states that “the focus of social scientific literature has been primarily on decision making rather than meaning making” (Layne, p. 625). The role of parents has often been studied in their relation to decision making rather how understanding and meaning is developed. Layne ascertains that growth and development of infants in the United States are viewed as a linear progression.
However, preterm infants in the NICU often do not follow a linear course, but more commonly have a course filled with bumps and setbacks. Infants who do not survive or suffer setbacks are not publicly discussed because these infants fall outside of the linear progress. Layne believes that the failure to discuss these infants “exacerbates the experience of parents whose babies do not have sterling careers as NICU patients” (p. 642). The diversity of the neonatal course and outcomes in preterm infants must be discussed in an effort to construct a realistic realm of possibilities and not just highlight “miracle babies” (Layne, p. 641).

Preterm births defy the linear progress concept offered by Layne (2000). Pregnancies that end too soon resulting in the birth of a preterm infant fail to follow the societal expectation of 40 week gestational course resulting in a healthy baby. In her ethnography, Gail Landsman (2009) proposes that the increasing medicalization of pregnancy and birth has created a societal belief that mothers have control over their pregnancies. Mothers who follow the prescribed regimen of prenatal care have healthy babies. Alternatively, those mothers who do not have healthy babies must have done something wrong (Landsman). The concept of “mother-blame” has become culturally embedded through this belief that women have control over their pregnancy (Landsman, p. 23). This concept is illustrated within March of Dimes posters that display the footprint of a preterm baby next to the foot print of a full size baby and the caption reads “Guess which baby’s mother drank while she was pregnant?” (Landsman, p. 26). The intent of this poster is to educate mothers about the harm of alcohol to the fetus; however, underlying message is that mothers’ behaviors determine the health of their infants. Therefore, if the infant is not healthy, the mother must be the cause.
Landsman further established maternal responsibility for having a “perfect” baby extends prior to pregnancy. In campaigns intended to educate mothers about pregnancy health, mothers are encouraged to plan in order to ensure healthy babies. Landsman found that the concept of maternal blame was embodied by women in her study. The women in this study repeatedly explained their belief in “doing everything right” would ensure a healthy pregnancy and delivery (Landsman, p. 17). They frequently looked for causes of their child's disability within themselves. This was confirmed by doctors who often place the cause of the problem within the environment of the uterus. Furthermore, Landsman believes that as mothers seek to identify what they “did wrong” they perpetuate the dominant cultural belief that mothers control the outcome of their pregnancies through correct choices (p. 31).

The concept of maternal control over pregnancy was also explicated by women who experience preterm labor. Mackey and Boyle (2000) used explanatory models to understand how women described, interpreted, and managed the preterm labor experience in the U.S. All women in the study believed that stress played a significant role in their preterm labor. This was exacerbated by the hospitalization to treat the preterm labor. They had significant worries regarding what was occurring at home while they were hospitalized. The women believed if they successfully managed the stress that preterm birth could be avoided.

Expectations and beliefs regarding pregnancy and birth are socially and culturally embedded. Preterm labor and delivery disrupt the expected prenatal course initiating parents to begin constructing the meaning of an unanticipated and unwelcome event, the end of a pregnancy in less than the full term gestation. The concepts of maternal
control over pregnancy and maternal blame for birth related outcomes have significant implications for the well-being of families. Calam and associates (1999) reported 79% of mothers and 92% of fathers who experienced preterm deliveries had unhappy or very unhappy feelings regarding the event.

The fathers’ perspective is often not addressed when considering preterm birth. Lindberg and associates (2007) interviewed fathers in Sweden whose infants were born preterm. The fathers expressed disbelief regarding the impending preterm delivery. After the delivery, they attempted to gain control over the situation by seeking information concerning the infants’ condition. Furthermore, they felt the need to protect and be responsible for both the mother and the infant. Worry about the mothers’ condition and their ability to handle the situation was pervasive. The need to be with both mother and infant was perceived as very stressful. One father expressed this as being the worst part of the situation because he always felt he was in the wrong place (Lindberg, Axelsson, & Ohrling). In a 2009 study of Taiwanese fathers, the themes of disbelief of the impending birth and providing protection for the mother and baby were repeated (Lee, Long, & Boore, 2009).

Golish and Powell (2003) used a dialectical framework to examine the grief process in families who experience ambiguous loss surrounding premature birth. Although the baby was alive, the parents had feelings of despair. They grieved the loss of the normal pregnancy and their child’s health status. Researchers described the contradictory feelings of joy and grief parents experienced when their infant was born prematurely. Shock, sadness, and anger regarding the birth were expressed by the parents while they also expressed overall joy regarding the baby. The grief-joy
contradiction was accompanied by the contradictions of acknowledgment-denial, control-helplessness, certainty-uncertainty, and openness-closedness (Golish & Powell). The parents expressed feelings of denial, disbelief, anxiety, sadness, anger and jealousy, guilt, and self-blame. These tensions inhibited the parents from managing the grief because the loss was intangible to them. There is certainty that the baby is alive, but uncertainty of the future of the baby (Golish & Powell). During this time, the mothers’ emotions vacillated between joy and grief. The loss the mother has experienced and its associated grief have to be acknowledged. The construction of illness meaning and implications is occurring within the grieving process.

Mothers are experiencing an extremely stressful and uncertain event in their lives when they have prematurely given birth. They are vacillating in their emotions between joy and grief (Golish & Powell, 2003). This is important in understanding the context in which they are developing the meaning of IVH and its subsequent implications. The mother is faced not only with constructing the meaning of the illness, but also with the meaning of her loss.

**Parental Experience in the NICU and Long Term Illness**

Parental experience in the NICU is expected to be influenced by many circumstances that may include prior illness experience, gestational age of the infant, and complications as a result of preterm delivery. Although specific circumstances may differ, several themes are clearly present in the studies reviewed. Separation increases fear and decreases understanding. Parents did not have landmarks to help them negotiate through the environment and situation in which they found themselves. The need for information to construct meaning of the situation was repeatedly revealed. Parents oscillate in their emotions: hope-hopelessness, happiness-grief, and
ambivalence-love. The parental emotions of shock, guilt, uncertainty, loss, fear, and grief were demonstrated in all the experiences.

Jackson, Ternestedt, and Schollin (2003) researched the experiences of parents in Sweden from the birth of their preterm child through 18 months of age. The researchers interviewed parents at four time points and synthesized a time-dependent process with four stages of experience: alienation, responsibility, confidence, and familiarity (Jackson et al.). During the alienation phase, mothers described feelings of ambivalence and not feeling like a part of the process. They felt happiness about the baby, but grief about the premature birth. Mothers expressed concerns that their infants would die. The environment was overwhelming to some mothers to the point that they found it difficult to participate in care. During the phase of responsibility, the mothers described feeling insecure and ill-prepared to care for their infants. Due to worry about the baby, mothers assumed roles similar to the NICU staff in which they were constantly monitoring the baby. This created stress and fatigue in the mothers. By the six month time interval, mothers were feeling more adjusted to the routine; however, they continued to be hypervigilant. At 18 months, mothers were more secure in their roles; however, they continued to describe feelings of loss and guilt related to their pregnancy and birth experience (Jackson et al.). This study demonstrates the evolution of maternal response to preterm birth over time.

Taiwanese mothers described NICU experiences in a 2009 study by Lee, Long, and Boore. Twenty-six mothers were interviewed and the data were analyzed using grounded theory. Three broad categories emerged: a new lived reality, barriers to parenting, and support systems. The women described being in disbelief that they had
delivered a preterm infant. One mother described “the world suddenly turned upside down” (Lee et al., p. 329). Doubt, fear, and sadness were all emotions expressed. Over time, the women depicted slowly integrating their experience to create a new reality. One mother described this as “reality was slowly dawning on me” (Lee et al., p. 329). Barriers to parenting were the NICU environment, lack of knowledge, appearance of the infant, and the traditional cultural practice of Zuo Yue Zi (one month of postnatal rest). Social support was found in four areas: health professionals, family, other NICU parents, and spiritual beliefs. As seen in the Jackson and associates study in Sweden, over time the mothers became more confident in their ability to care for their infants as more physical and emotional connections with the infant were made.

Mothers in Sweden described their experiences in a unit that provided co-care for mothers and sick infants (Erlandsson & Fagerberg, 2004). The researchers in this study developed categories of being close to the baby and not, being seen and not, and being part of a team and not. All the mothers overwhelmingly wanted to be close to their babies. Mothers who were able to have open access to their infants felt confident in being able to care for their baby, their needs were better understood by the staff, and they felt more control over the situation. When the mothers were separated from their babies, they experienced feelings of guilt, abandonment, and disconnection from their babies. They reported confusion regarding the information that was provided to them in regards to the baby’s condition and treatment. Their own needs were forgotten and promises made to them by providers were broken (Erlandsson & Fagerberg).

In Hall's (2005) study of Danish parents' experiences when their newborn or small child was critically ill, parents described being in an alien world. They had no landmarks
to help them negotiate. Subthemes included a need to be there, what is going on, being vigilant, being a spectator, and oscillating between hope and hopelessness (Hall). Parents expressed the need to be physically close to their children. They wanted to know what was happening, not just the diagnosis, but actual care and treatment. Parents were watchful of everything and described instances of recognizing changes in the child before the staff. Descriptions of feeling as if they didn’t belong in this alien environment where they watched, but did not know what was happening were given by parents. Feelings oscillated between hope and hopelessness as the status of their child changed or did not change. Hall quoted one mother as saying “I could not believe that he would survive, I did not dare get close to him, I did not know if I was going to keep him, if he was dying or what was happening” (Hall, p. 182-183).

The overwhelming environment of the NICU was a major focus in Gavey’s (2007) retrospective study in which she interviewed parents of 16 infants born preterm and admitted to the NICU. Parents described having to adjust to the milieu and routines. One description of the NICU included “and then the first time we went in the room, it was dead shocking” (Gavey, p. 201). Overall, the parents felt well informed about their infants’ condition and treatment. A father described the personnel who was on duty one particular night as “my own personal consultant” (Gavey, p. 202). As noted in other studies, the inability to care for the infant and sometimes restricted access caused a feeling of distance and judgment. A mother stated “I felt like a part time mum at first” and another mother stated “I got told off by one (of the nurses) for doing his cares one way” (Gavey, p. 202 & 203). Unexpected changes, such as the moving of the infant’s bed space, were difficult for the parents to handle if they had not been notified.
Lupton and Fenwick (2001) interviewed 31 Australian mothers whose preterm infants were hospitalized in one of two hospitals. “Practicing motherhood” in the NICU was described as a constraining and public event which required them “to jump through hoops” (Lupton & Fenwick, p. 1012, 1016). This created a sense of distance for the mothers. The mothers felt “alienation, despair, and grief” and “were not prepared for motherhood to arrive so quickly” (Lupton & Fenwick, p. 1014).

In a Finnish based study, the experiences of parents of children with long term illnesses were described (Nuutila & Salantera, 2006). The researchers focused on the ways that healthcare professionals affect the experiences of parents when their child is hospitalized. Experiences were evaluated in three distinct phases: diagnostic, learning care, and successful coping (Nuutila & Salantera). During the diagnostic phase, parents described shock and chaos. They needed information to help organize their thoughts and understand the situation. If parents received conflicting information, they developed distrust of providers. During the learning care phrase, parents felt scared, uncertain, and inadequate. Encouragement by the staff was seen as helpful; however, parents feared judgment by the staff regarding their decisions. During the coping with care phase, parents continued to feel uncertain, but they were able to recognize their ability to care and make decisions for their child. Parents began to think more about their child’s future (Nuutila & Salantera). This study again demonstrated the need to view the construction of meaning and understanding as an experience-dependent process.

Experience in the NICU is likely to be affected by many factors, including the health of the preterm infant. In a study by Padden and Glenn (1997) conducted in
England, mothers were overwhelmingly satisfied with their preterm birth and NICU. Of the 36 women interviewed, 27 women described themselves as “lucky” (Padden & Glenn, p. 128). An important difference to note in this study is that none of the infants were considered "medically fragile," furthermore, none of the infants required mechanical ventilation at 48 hours of age (Padden & Glenn). This would seem to endorse the belief that the meaning created regarding preterm birth is highly contextual, but may be more closely linked to the health of the infant than cultural variations.

Several studies have found that uncertainty was a major factor in the lives of parents whose children were critically ill. Cohen (1993) studied parental behavior during time of childhood illness using a grounded theory approach and found the uncertainty pervaded every aspect of the family’s life after diagnosis. The parents were constantly uncertain about their child’s survival (Cohen; Santacroce, 2003; Hall, 2005; Jackson, Ternestedt, & Schollin, 2003).

**Maternal Well-Being**

Maternal well-being and infant attachment is believed to be an important dimension of the preterm birth experience. Entering parenthood within the NICU has been described as a particularly stressful event. The physical separation from the infant has been demonstrated to increase fear and uncertainty. These events have the potential to negatively affect mothers’ overall well-being and attachment process.

Garel, Dardennes, and Blondel (2006) described psychological distress in mothers one year after preterm childbirth. Results were reported in terms of maternal fatigue, feelings of guilt, anxiety, perception of child’s behavior, post-traumatic sequelae, defense mechanisms, maternal health, and infant’s development and health. Two-thirds of the mothers expressed fatigue. Depressive affects were noted in 16 of 20...
mothers. Feelings of guilt and anxiety related to the preterm delivery and the baby’s health and development were frequently reported. Two-thirds of the mothers described their children as difficult. Half reported post traumatic symptoms such as avoidance or reliving the experience. During analysis, defense mechanisms such as denial, idealization, minimization, and rationalization were identified (Garel et al.). This study exemplifies the broad effects of preterm birth on mothers.

Reichman, Miller, Gordon, and Hendricks-Munoz (2000) studied stress appraisal and coping in mothers of NICU infants. The purpose of the study was to investigate mothers’ responses to premature birth with particular emphasis on coping response and psychological functioning. Anxiety was found to be the most prevalent symptom of stress (Reichman et al.). Social support was not found to have a significant effect on functioning; however, satisfaction with the infant’s doctor was associated with improved functioning and lower levels of perceived uncontrollability (Reichman et al.).

The nature of maternal attachment in the NICU was described by Bialoskurski, Cox, and Hayes (1999). The dichotomous concepts of overt and covert attachment processes were identified. These processes were affected by infant and maternal health, environmental circumstances, and quality of care. The researchers found the attachment process was not automatic for mothers. Immediate attachment was more likely to occur if there was physical contact between the mother and infant immediately after birth. Delayed processes were more likely to occur in mothers who experienced premature births. This may be a result of the baby not conforming to expectations of a healthy newborn or it may represent a grief coping strategy. Attachment is usually a dyadic relationship between the mother and infant; however, in the NICU the mother
shares her baby with the nurse which may complicate the relationship (Bialoskurki et al.). Maternal attachment to her baby is a multifactorial process that is affected by many extrinsic and intrinsic factors. Nurses may enhance the process of attachment in the NICU by promoting physical contact with the infant early and providing opportunities to care for the infant (Bialoskurki et al.). The mother’s level of attachment to her infant may affect the meaning of IVH she constructs; therefore, maternal attachment is an important consideration.

Psychological distress may be present after a traumatic event such as preterm birth. Preterm birth and its repercussions results in maternal stress and anxiety which may last well after hospital discharge. This may have lasting effects on the maternal-child relationship.

**Provider-Family Interaction**

Provider-family communication is another important concept that emerged in the literature review. Parents have an overwhelming need for information often times for information that is unknowable (Payot, Gendron, Lefebvre, & Doucet, 2007; Alderson, Hawthorne, & Killen, 2006). Although parents expressed the desire for information, the information was often confusing, unclear, and ambiguous (Alderson et al.). Parents desired communication to be a two-way process and did not want to simply receive information regarding the scientific facts (Alderson et al.; Payot et al.; Abrams & Goodman, 1998).

Parents experiencing an impending preterm delivery may be inundated with information regarding the actual delivery process and why it is occurring. During this time, consults with neonatology are common to prepare the parents for the possible needs of the preterm infant. Griswold and Fanaroff (2010) article published in
*Pediatrics* that the goal of “prenatal consultation is to share prognostic information with parents. Parents must understand potential outcomes, both short- and long-term, for their premature infant so that they may make an informed decision regarding neonatal resuscitation and treatment” (p. e933). However, it remains unclear if these goals are possible to accomplish in a preterm birth setting.

Calam and associates (1999) interviewed mothers of 76 preterm infants to assess the recall and understanding of information provided by healthcare professionals regarding their infants. They reported that 25% of mothers could not recall any information provided immediately after delivery and that 30% did not understand the information provided. The type of delivery was not found to influence the amount of recall by the mother. Forty-five percent of infants in the study were considered at risk for cerebral palsy due to complications, yet the mothers continued to have an optimistic view of future outcomes (Calam et al.). The researchers indicated that the mothers may not have interpreted information provided that indicated profound future difficulties. This has major implications for the timing of information dissemination. As previously discussed, many mothers are provided information regarding IVH within days of delivery. The findings of this study clearly imply that mothers may not be ready to interpret this complex information.

Alderson, Hawthorne, and Killen (2006) used an ethnographic approach to investigate parental views regarding information dissemination and care decisions within the NICU. Experiences and information sharing was presented through the perspective of parents. They described the shock and fear they felt seeing such a small infant that was so different from what they had expected (Alderson et al.). One mother
expressed shock regarding the overwhelmingness of the environment “It is so hot and so bright and so noisy . . .” (Alderson et al., p. 1321). Mothers also described helplessly observing interventions being performed on their infants, while others were separated from their infant not knowing what was happening to them. There was a wide range of feelings related to communication of information regarding the baby. Some parents felt they were given too much information too soon and others felt that professionals had missed opportunities to provide critical information they needed to make decisions with significant consequences (Alderson et al.). They expressed the desire to be warned of severe problems, but were distressed if they had been told of problems that did not develop. Parents wanted to be involved in the decision making or consent process. They did not simply want to receive the information. They expressed a desire to share information as a two-way process in order to make decisions in the context of grave uncertainty (Alderson et al.). This study provided insight into the mothers’ emotional states as well as information exchange. The variation in desire to receive information may be explained by the health status of the infant. Receiving information regarding potential complications that did not occur may have created more worry in mother’s infants with less severe conditions.

Payot, Gendron, Lefebvre, and Doucet (2007) developed two models which they believed neonatologists use to prenatally convey diagnosis to parents and assessed how these affected overall parental experience after six months. The concept of different projects was described as the neonatologist and parent having divergent agendas or “projects” (Payot et al.). They are complimentary, but different. The neonatologist’s goal is to determine a plan of care for the baby. The focus is on
prognosis, mortality, morbidity, sequelae, and disability. However, parents are focused on the parenthood project. They are confronted by grief and loss of a normal pregnancy and, possibly, a normal family. Parents frequently had associated guilt. The use of information was also different between the neonatologist and parents. The goal of the neonatologist was to provide objective, neutral information, so as not to influence the parents’ decision. The parents had to reformulate statistics provided into terms of the “chances” of their infant’s outcome (Payot et al.). When attempting to “come to the right decision,” neonatologists expressed concerns as to whether the parents understood the information conveyed to them and parents expressed a need for more than scientific information (Payot et al.). They often felt detachment and a lack of support. According to Payot et al., this affected the outcome of the experience more than the decision itself. The researchers suggested engaging into a shared space between the neonatologist and parents not only to exchange scientific facts, but to explore values and expectations. In this study, parents clearly expressed that scientific information was not enough to address the complex decision making that needed to occur. This study addressed prenatal communication. Once the infant is born, the ability for parents to address the baby as a separate entity may change the dynamics of decision making; however, the complexity of the medical decision making still cannot rely on statistics alone and must be understood within a sociocultural context.

Abrams and Goodman (1998) examined how parents and professionals negotiate diagnostic labels and the meanings of those labels in the context of developmental problems. Analysis demonstrated that the diagnosis and meaning were constructed jointly between the provider and the parent. Diagnosis, severity, and outcomes were all
negotiated through reversals and reiterations between the provider and the parent. Meanings of labels were not always the same between providers and parents. The meaning was often “flushed out” (Abrams & Goodman, p. 93). Use of vague terms led to parental confusion. The authors offer the suggestion to providers when discussing “bad news” with parents to invite negotiation as a means of jointly creating the meaning of the diagnosis (Abrams & Goodman, p. 96).

Communication of a diagnosis is a process in which both parties participate. The area of physician-family or patient communication has often been reported as an area of dissatisfaction (Calam et al., 1999; Fox et al., 2005; Lazarus, 1988). Negotiation occurs as the parents attempt to construct meaning of the diagnosis and illness in terms of their sociocultural beliefs and experiences. The meaning cannot simply be given to the parents and statistics are not enough to help the parents make the complex decisions they face. The “shared space” described by Payot et al. (2007) can be viewed as an invitation to negotiate meaning in terms of the parents’ beliefs.

In order to develop better understanding of this complex situation, the context in which information exchange and decision making is occurring must be acknowledged. There are many sociocultural elements, beyond individual beliefs, to be considered such as power dynamics in the social interactions between families and healthcare providers. Greater understanding of the process by which mothers construct meaning of the diagnosis and subsequent implications of IVH is needed in order to support them through the many complex decisions they will have to make regarding current and future care of their child.
Explanatory Models

In a perinatal study, Lazarus (1988) investigated the provider-patient relationship in a perinatal clinic using two approaches explanatory models and critical anthropology. The explanatory model is a cognitive approach focusing on the individual meaning of sickness and health (Kleinman, Eisenberg, & Good, 1978); whereas, critical anthropology focuses on the conflict inherent within social relationships (Lazarus). In her ethnographic study of women and providers in an inner city perinatal clinic, she found that provider and patient explanatory models (which she refers to as disease models) did not differ between the patients and their providers. However, the women did not have fulfilling relationships with their providers due to the social interactions. Their expectations of the social interaction during the visits were consistently not met. Lazarus and associates believe this is how the power and knowledge differential are expressed within the provider-patient relationship. She recognizes that individual meaning, beliefs, and experiences should not be discounted. The challenge is to capture the complete context by merging individual meaning with the larger social system of healthcare to achieve encounters that meet social expectations while acknowledging the individual belief system.

The construction of a framework used to understand cerebral palsy in a family living in a kibbutz, a communal settlement, in North Israel was described by Borkan, Yeheskel, and Biderman (1993). The family and community understood the birth of a child in terms of healthy children who would develop normally and become productive citizens. However, a family in the kibbutz had a child who was delivered prematurely, suffered an intraventricular hemorrhage, and subsequently developed cerebral palsy. The family had difficulty providing for the demanding needs of their daughter. They
missed time from work, spent less time with their other child, and experienced
deterioration of their health. The community also lacked understanding and felt it was
impolite to discuss the child’s diagnosis or prognosis thereby making it difficult for the
family to express their needs. An intervention was started by the healthcare team on
the kibbutz to help the family and community develop a framework in which to
understand disability. The kibbutz explanatory model was based on a disease that
would eventually get better. The model was eventually reconstructed to incorporate
disability. This reconstruction allowed the community and family to reconnect and
develop an understanding of the family’s needs. The study supports the belief that
mothers may not have an established framework in which to understand the diagnosis
and subsequent complications of IVH. Exploration of maternal explanatory models may
provide insight into their interpretation and understanding of the diagnosis.

**Discussion**

Analysis of current literature related to socio-cultural beliefs, preterm labor and
birth, neonatal IVH, NICU experience, maternal well-being, physician-family interaction,
and illness meaning revealed several recurrent themes. Biomedicine dominates the
preterm birth experience. Mothers may look within themselves for the cause of this
event. Although the mothers felt the NICU environment was foreign and overwhelming,
they clearly indicated a need to be physically close to their infants. The mothers have
experienced an ambiguous loss for which they are grieving and may have associated
feelings of guilt. Many of the studies described an oscillation of maternal emotions that
may be conflicting, such as grief-joy, love-ambivalence, and hope-hopelessness.
Feelings of insecurity, stress, shock, chaos, fear, uncertainty were repeated throughout
the studies. The maternal attachment process may be affected when the infant is in the
NICU and separated from the mother. Attachment may be delayed or problematic as the mother attempts to deal with her loss. Communication between parents and physicians revealed a negotiation process that occurs around diagnosis meaning and severity. Parents repeatedly stated the need for information; however, they expressed a desire to receive more than statistical information about the diagnosis. Individual illness meaning may be elicited by using explanatory models as a method for individuals to express their beliefs about illness, therapies, and outcome goals. It is evident that mothers of prematurely born infants are confronted with circumstances that are overwhelming and unexpected within an environment, and often times a role, in which they are unfamiliar. This necessitates the rapid development of a framework in which to understand this unexpected event.

**Summary**

This review of literature illustrates the complex dynamics associated with preterm birth. It is not clear how these dynamics affect understanding and meaning development related to neonatal IVH by the mother. By more fully understanding the mother’s sociocultural beliefs and the context in meaning development is occurring, healthcare providers can negotiate a shared model of understanding. The use of explanatory models may facilitate this process on an individual level. Better understanding may allow the burden of decision making to be shared between the provider and family in a way that is acceptable and supportive to the mothers. However, the complex dynamics that affect maternal meaning of IVH diagnosis and illness beyond the individual level must also be understood. Standards of care related to preterm birth, environmental influences of the NICU, and power dynamics associated
with physician-patient relationships must also be examined. The following chapter addresses the methodology guiding this study.
CHAPTER 3
OVERVIEW OF THE METHOD

The purpose of this chapter is to provide a framework of the methodology used to conduct this grounded theory study. This description will provide an account of data collection and analysis which led to the explanatory model illustrating the development of maternal meaning of neonatal intraventricular hemorrhage. This chapter is divided into four sections. Section one is a discussion of symbolic interactionism (SI) and explanatory models which are the theoretical frameworks used to guide this study. Section two explains the tenets of grounded theory. This sections ends with a reflexivity statement that reveals my motivation for conducting this study, as well as experiences which may influence my interpretation of the data. Section three explicates the process of investigation including the sample, data collection, and data analysis using dimensional analysis. Section four is an explanation of the scientific rigor employed in this study. This section concludes with a discussion of the strengths and weaknesses of grounded theory and the current study.

Section 1: Theoretical Perspectives

Grounded theory seeks to conceptually explain social processes through the development of explanatory models that are firmly grounded in data (Eaves, 2001; Morse & Fields, 1995). It is rooted in symbolic interactionism, a sociological perspective used to conceptually understand human behavior through social interactions (Glaser & Strauss, 1967). Arthur Kleinman (1988) states that “biological processes are known through socially constructed categories” (p. 17). He proposes the use of explanatory models to understand an individual’s beliefs about the causes, effects, and cures of illness from within a cultural perspective (Kleinman). Cultural beliefs are created and
shared through social interaction. Therefore, concurrent use of these frameworks provides a perspective from which to explain the effects of social interaction and culture on the meaning of a phenomenon such as neonatal intraventricular hemorrhage.

**Symbolic Interactionism**

Symbolic interactionism is a sociologic perspective developed from pragmatism that seeks to understand human action through examining interactions between the self and the world (Glaser & Strauss, 1967; Blumer, 1969). Therefore, the individual, society, and actions are its essential principles (Charon, 2007). The focus of SI is the social actor, meaning the individual, in any given social system rather than the society itself (Bowers, 1988). Charles Cooley developed the concept of the “looking glass self” in which he proposed the self and society are one phenomena (Coser, 1971, p. 305). The identity of the self is created through three principles:

- One’s view of one’s appearance to another person
- One’s view of the judgment of this appearance by the other person
- One’s self-feeling regarding those views (Coser).

George H. Mead (1934) often identified as the father of SI, further described the self as a social product that is constructed through interactions. Therefore, the self is a composite of all the social interactions of which the person has been a part. Herbert Blumer, a student of Mead, further developed and summarized the perspective for the purpose of detailing topics such as methodology (Blumer, 1969). He described SI as being based on three premises. The first premise is that human beings act toward things on the basis of the meanings the things have for them. The second premise is that meaning is derived from social interaction among human beings. The third premise
is that meanings are handled and modified through an interpretive process used by the person in dealing with things that are encountered.

Interpretation makes this perspective distinctly different from other sociologic perspectives that only account for reaction not interpretation (Blumer, 1969). The first step in the interpretation of meaning is an internalized social process of communication within oneself in order to determine the things that have meaning (Blumer). The next step is to determine meanings in the current context (Blumer). Through this process, meanings may be revised as contextual changes occur then new meanings are used to direct subsequent action (Bowers, 1988).

The self, world, and social interaction are the three fundamental concepts contained within these premises (Stryker, 1980). The self is a social construction and is made up of the I and Me (Bowers, 1988, p. 36). The Me is constructed from birth through social interaction by taking on the role in which one is viewed by others; therefore, there are multiple Me’s in the self (Bowers). This can be described as social roles. The I is the interpreter of cues related to the Me (Bowers). Therefore, self is created through an ongoing of interpretation of the Me by the I. The world is another fundamental concept of symbolic interactionism. The world refers to the social world in which the individual interacts (Bowers). It is often referred to as the object world; however, it does not indicate the physical world in which human beings live (Bowers, p. 38). The object world is different for every human being because it is created through an accumulation of experiences. This implies that reality is different for each person (Bowers). Although, shared experiences within the world give rise to collective meanings in which humans can relate. The third concept relates to social interactions.
The interaction is based on the premise that individuals designate symbols to each other and to themselves (Bowers). The interactions occur based on how the person identifies himself and how the social world is perceived by the person and others. The individual then interprets cues “taking on the other” to determine actions and if the action should be changed (Bowers, p. 42).

Symbolic interactionism is based on the presumption that meanings are constantly evolving and do not remain static (Bowers, 1988). Actions are based on meanings or perceptions of a given situation (Charon, 2007). Perceptions are created between the self and social interactions through interpretation, but it is not the interaction itself that causes action but the understanding or meaning of the interactions for an individual (Charon). Reality is then created or negotiated between people through shared meanings, interpretations, and actions, also described as social production (Denzin & Lincoln, 2000; Richards & Morse, 2007). This perspective allows for individual meaning to be developed based on the cumulative and changing experience of the person within his or her social environment. It is important to keep in mind that individuals have multiple Me’s or social roles which are interpreted by the I. All social roles will comprise the person, but interactions and expectations will differ dependent on current social role.

Therefore, the development of situational meaning, such as an illness occurrence, will be an individualized process with the possibility of multiple meanings that may change over time. This is a dynamic process. When the social role of the Me is a maternal caregiver, meaning of the situation will be interpreted through that lens as social interactions occur. Actions will be guided by the meaning or perceptions developed from the interactions.
Explanatory Models

The meaning of an illness experience is shaped by many sociocultural factors, such as perceptions, explanations, labels, values, rules, expectations, and experiences, all of which are embedded and exchanged within an intricate social system (Kleinman, Eisenberg, & Good, 1978). Using these factors, both healthcare providers and patients' create a “clinical reality” that is part of their larger explanatory model of a particular illness (Kleinman et al., p. 254). An individual’s explanatory model is the way in which an illness is understood through his or her sociocultural perspective. Kleinman (1988) proposes that healthcare professionals should deliberately elicit the patient's or family’s explanatory model for a given illness. This will allow the professional to understand the beliefs and social meanings related to the illness, as well as expectations related to the etiology, pathophysiology, symptoms course, and treatment (Figure 3-1). Kleinman has proposed eight questions focusing on etiology, symptoms, pathophysiology, course, and treatment that professionals can use to guide their elicitation of an explanatory model (Figure 3-2).

Kleinman (1978) developed the Explanatory Model Framework as a way to understand illness meaning; however, the framework has been used to study other social phenomena. Biering (2007) adapted the framework to study youth violence from the perspective of adolescent males, adolescent females, and their parents. Although all components of Kleinman’s framework were not pertinent to studying violence, such as pathophysiology, Biering concluded that it could be used in social science research to understand causes, course, and possible solutions to social problems. Reiss (1981) describes explanatory models of families as critical guides to action. The belief systems
that families develop and share are used in times of crisis to make meaning and react to the situation.

Kleinman (1988) describes explanatory models developing from interactions within a social system and then guiding action, which is consistent with the tenets of SI. Social interactionism provides the underpinnings for grounded theory, which was created for the purpose of generating explanatory models of social processes that are grounded in data (Morse & Field, 1995) and was used as the theoretical perspective to guide this study. In this study, maternal explanatory models, as defined by Kleinman, were elicited as a way of understanding a particular socially-produced reality, meaning of neonatal IVH.

**Integration of Frameworks**

The theoretical perspectives of symbolic interactionism and explanatory models were integrated in this grounded theory study. The tenets of the perspectives are complementary allowing their simultaneous use to understand complex phenomena. Explanatory models are explanations or meanings of phenomenon, usually illness, from a cultural perspective. These meanings are developed from sociocultural experiences. Symbolic interactionism asserts that meaning is based upon social interactions and that meaning guides action. Multiple meanings of a particular reality are possible based upon factors such as expectations and experiences. Therefore, the simultaneous use of these perspectives allowed meaning to be elicited and its influence on action to be understood.

In this study, exploring the maternal meaning of neonatal intraventricular hemorrhage was approached from the viewpoint that illness meaning is developed from a complex sociocultural interaction that is dynamic in nature. Development of a
framework to understand illness meaning requires a time of intense social interaction (Reiss, 1981). It is theorized that mothers in this study may not have an explanatory model for neonatal IVH due to a lack of social exposure. The time following diagnosis will likely be an intense time of meaning making for these mothers. Neonatal intraventricular hemorrhage is far too complex to be explained by statistical figures often offered by healthcare providers, as the sociocultural context must be considered.

Maternal meaning is constructed through social interactions and cultural interpretation, which are influenced by the acquisition of a new social role, previous life experiences, social expectations, perceptions, and values. The mother then acts based upon the meaning constructed. This process is illustrated in Figure 3-3. The maternal meaning of IVH evolves with increasing experience and changing contexts, resulting in evolving responses to the diagnosis.

Section 2: Methodology

Grounded theory is a naturalistic, systematic research methodology based upon the tenets of SI used to understand experiences from the participants’ perspective that have not been well researched (Glaser, 1992; Glaser & Strauss, 1967; Strauss, 1987; Strauss & Corbin; 1990). It was first developed by Glaser and Strauss as a method to study and understand social phenomena. The original purpose of this methodology was to create substantive or formal theory that emerged from data (Glaser & Strauss). This is an alternative to traditional quantitative methods that test theory using predetermined variables and relationships. Grounded theory uses inductive and deductive reasoning iteratively to generate theory that is grounded in rich empirical data (Charmaz, 2006). The generated theory is a construction of reality based on the interpretive analysis of the participants’ views (Charmaz). Theory generation requires the use of rich data
typically gathered through intensive interviews and observation (Bowers, 1988; Charmaz). It can be viewed as an explanatory model of the particular social phenomenon under study. The goal of grounded theory is to move beyond the description of an experience toward a broader conceptual understanding of complex phenomena (Charmaz; Schatzman, 1991).

Constructivist grounded theory was the method chosen to guide this study. Charmaz (2006) states “Constructivists study how –and sometimes why- participants construct meanings and actions in specific situations” (p. 130). This qualitative method is the most appropriate to address the specific aims of this study because there are no theories explaining how mothers of preterm infants construct meaning and understanding of neonatal IVH. This method allows the complexities associated with constructing the meaning and implications to be better understood by analyzing multiple dimensions of the phenomenon and developing substantive theory that is generated through the interpretation of the mothers’ reality. Charmaz proposes that grounded theory not be viewed as a set of procedures. “Rather, we can view grounded theories as products of emergent processes that occur through interaction. Researchers construct their respective products from the fabric of the interactions, both witnessed and lived” (Charmaz, p. 178). The theory developed is a construction of reality based on the interpretative analysis of the participants’ views as described by Charmaz.

**Historical Roots**

Grounded theory was developed by Glaser and Strauss (1967) in the 1960’s as a method by which to study and understand social phenomena using the symbolic interactionism perspective. Glaser and Strauss incorporated competing traditions of positivism and pragmatism together to develop the grounded theory method (Charmaz,
Glaser trained in positivist traditions focused on rigorous methods by emphasizing explicit strategies (Charmaz). Strauss was trained in a pragmatic philosophy which informs symbolic interactionism and focuses on reality construction (Charmaz). Together they developed a rigorous method that focused on meaning production as experienced by participants. Using the processes of theoretical sampling and comparative analysis, knowledge is created about how individuals interpret reality (Suddaby, 2006)

After the original publication, the two authors developed distinct approaches to this method. Glaser’s method is more objective; the researcher remains neutral in discovery and focuses solely on the “data” for emerging components of theory that focus on a basic social process. Alternatively, Strauss’ method considers “all data” including the researcher’s thoughts and reflections (Richards & Morse, 2007). Glaser (1978, 1992) continued to explicate theoretical sampling, coding, and memo writing with a focus on emergence while rebuking the newer Strauss (1987) and Strauss and Corbin (1990) as conceptual description. Glaser’s style of grounded theory is generally thought of as objectivist, which is from a positivist tradition and assumes that the researcher is discovering objective facts that exist in the world (Charmaz, 2006). Strauss (1987) and Strauss & Corbin (1990) developed a constructivist approach in which theory is an interpretation of the shared experience. They further explained coding strategies and deviated from the original method by providing predetermined data categories while continuing to assume multiple perspectives of reality are possible (Charmaz).
Since this time, Charmaz (2006) has proposed a constructivist approach in which flexibility in grounded theory is utilized. However, she has proposed six tenets of all grounded theory:

- The research process is fluid, interactive, and open-ended.
- The research problem informs methodological choices in data collection.
- Researchers are part of the study.
- Analysis shapes the content and direction of the study.
- Successive levels of abstraction through constant comparison constitute the core of analysis.
- Analytic direction comes from researcher interaction and interpretation of comparisons and emerging analysis (Charmaz, p. 178).

In conclusion, grounded theory can be viewed as a method to interpret an individual’s view of reality using a variety of processes to produce a theory that has credibility, originality, resonance, and usefulness (Charmaz).

**Constructivist Grounded Theory**

The two components of grounded theory are the research team and the data. Grounded theory should not be performed alone, but rather using a team to ensure the emerging theory is grounded within the data. The researcher is the tool used to gather the data (Strauss, 1987). The researcher becomes intimately involved with research participants, attempting to place themselves into their world, in an effort to understand the participant’s perspective while maintaining enough distance to analyze the phenomenon (Bowers, 1988; Strauss). Once data are collected, analysis for codes, concepts, categories, and finally theory occurs (Glaser & Strauss, 1967). The phases of the research process occur simultaneously in an iterative process (Glaser; Glaser & Strauss; Strauss; Bowers). As data are analyzed through the constant comparative
method, interview questions, sampling, and research questions are revised to reflect the findings (Glaser; Glaser & Strauss; Strauss; Bowers). This process allows the study to develop throughout the iterations. Glaser and Strauss recommend collecting and analyzing data prior to performing an in-depth literature review so as not to attempt to force the data into preconceived categories. As the data are coded, categories emerge. These categories are also constantly compared in order to develop the relationships between them. Theoretical sampling is employed to allow deeper study of a particular concept or in the development of new concepts. In order to accomplish this, the researcher must be theoretically sensitive to know what the data are revealing (Glaser & Strauss).

**Sampling**

Purposive sampling is used in grounded theory to recruit participants who fit established research criteria. As data analysis occurs, theoretical sampling is used to guide further data collection specifically related to the emerging categories. Theoretical sampling is a type of purposive sampling based upon the iterative process of data collecting, coding, analysis, and planning in grounded theory (Glaser & Strauss, 1967). Theoretical sampling may require adding participants or interviewing a participant again about a specific phenomenon. Theoretical sampling enhances the analysis by further delineating a category, saturating a category, distinguishing categories, and clarifying relationships between categories (Charmaz, 2006). Sampling concludes when the categories have reached saturation. According to Glaser (1992), saturation is reached when the addition of data reveals no new properties of the patterns that have emerged. The determination of saturation is not based upon a particular numeric value. The
constant comparative method and the use of memo writing provide guidance in determining the saturation of a category.

**Coding**

Data analysis begins with initial line by line open coding (Charmaz, 2006). These codes closely reflect the action in the data. In vivo codes are included where appropriate to use the participants own words in the descriptions (Charmaz). The initial codes are used to separate data into categories in the next level of coding. Throughout coding, ideas continually emerge, requiring the researcher to return to previous data for continued comparison. Focused coding comprises the second phase of coding. This type of coding focuses on significant codes and classification of concepts into categories that most analytically and completely categorize the data (Charmaz). These codes are more conceptual than the initial codes. Axial coding is the third phase of coding that may be employed. In this phase, characteristics, properties, and dimensions of the categories are explicated. This can be used as a framework in which to organize codes into a scheme such as context, conditions, processes, and consequences for the purpose of linking categories and subcategories (Charmaz). Theoretical coding is a final coding step that may be employed to help delineate linkages or relationships between categories (Charmaz). At this stage, data that has been fractured in earlier coding is linked together to explain theoretical relationships.

**Constant comparative method**

Constant comparative analysis is the foundation of grounded theory and involves comparison throughout analysis (Glaser & Strauss, 1967; Charmaz, 2006). Once the data has been deconstructed through line by line coding, comparisons are made among data within interviews and between interviews. Using this process, data or incidents are
compared (Glaser & Strauss). The data are compared to the codes, and further, the
codes and categories are compared. Emergence of new ideas requires a return to data
for comparison to previous codes, categories, and relationships (Glaser & Strauss).
This process is implemented throughout the research process. During the analysis,
data from interviews are compared with data from other participants. If a participant is
interviewed more than once, the interviews are compared. The initial open codes of the
interviews are compared. This will ensure consistency in the coding and allow for
emergence of categories. As the categories emerge, they are constantly compared to
the codes and with each other.

**Dimensional analysis**

Dimensional analysis (DA) is the method of data analysis used in this study that
utilizes the coding procedures and constant comparative method previously described.
It is a research approach that employs naturalistic analysis and dimensionality to
identify and explain the concepts of a phenomenon in order to understand its complexity
and meaning (Bowers & Schatzman, 2009). This approach was developed by
Schatzman to explicate the way in which data analysis occurs in a grounded theory
study; therefore, it is rooted in grounded theory and based on the sociologic perspective
of symbolic interactionism (Schatzman, 1991). It maintains the assumptions that "reality
is socially constructed, defined from a particular perspective, and is contextually
situated" (Caron & Bowers, 2000, p. 288).

The aim is to answer the question “What all is involved here?” by expanding the
conceptual possibilities in order to “discover the meanings of interactions observed in
situations” (Schatzman, 1991, p. 310). This is achieved in early analysis through
identification of possible dimensions or attributes of a phenomenon through coding or
dimensionalizing. All codes are considered dimensions of the phenomena at the contextual level (Schatzman). Through ongoing analysis, the investigator identifies the central dimension that possesses the most explanatory power of the relationship between the dimensions (Schatzman; Kools et al., 1996). Any dimension has the theoretical possibility of being the central perspective around which the other dimensions are organized. This central dimension becomes the perspective through which the remainder of the analysis occurs. Once the perspective is identified, the remaining dimensions are categorized as context, conditions, processes, and consequences (Schatzman). According to Kools and associates, context is the category that contains dimensions that are more peripheral and refer to the situations in which the dimensions occur. Along with perspective, context helps to provide the boundaries to determine the relevance of the other dimensions (Schatzman). Conditions are the most salient dimensions and have an influence on action and interactions. Processes include actions and interactions that are intended or unintended that are actuated by specific conditions. The consequence is the outcome of the actions. This is the explanatory matrix (Figure 3-4) in which the dimensions are organized and the final theory will be developed (Schatzman; Kools).

The development of the explanatory matrix is an iterative process in which sampling, coding, and dimensionalizing occurs simultaneously. Kools and associates (1996) provide the following depiction of the iterations. Purposive sampling is used to acquire data relevant to the phenomenon of interest until a “critical mass” of dimensions is achieved (Schatzman, 1991, p. 310). Dimensionalizing or open coding of the data is performed, followed by axial coding in an effort to condense the dimensions into
categories that are related. Theoretical coding then allows links to be created among the dimensions. Once the perspective is identified and the remaining dimensions are categorized, theoretical sampling and constant comparison are employed to verify or refute the organization of the dimensions within the explanatory matrix. Once theoretical saturation has occurred (consistent repetition of concepts with no new features identified), dimensional relationships are constructed around the central perspective to create a theoretical explanation of the phenomenon created from the data (Kools et al.). Schatzman (1991) describes the final product as giving “theoretical and explanatory form to a story that would otherwise be regarded, at best, as fine description” (p. 313).

**Memo writing**

Memo writing is used throughout the research process to serve as a record of the theory development (Strauss & Glaser, 1967; Bowers, 1988; Charmaz, 2006). The memos document decisions regarding sampling, questioning, coding, category development, concept emergence, and relationships. Memo-writing is a critical part of the analytic process and will serve as an intermediate step between data collection and theory generation (Bowers). This process describes the connections made throughout the research process and enhances the process by revealing areas that require further development (Charmaz).

**Sorting**

The process of sorting, diagramming, and integrating memos provides the means for creating and refining theoretical links (Charmaz, 2006). Category comparison and memo sorting occur simultaneously. The relationship between categories emerges as a result of the sorting. Diagramming is used as a visual representation of the
relationships (Bowers, 1988). From this process, a substantive theory is developed that explains the phenomenon under study.

**Reflexivity Statement**

In grounded theory, the researcher is the tool used to gather data (Strauss, 1987). The researcher becomes intimately involved with study participants, attempting to place themselves into the world of the participant in an effort to understand the participant’s perspective while maintaining enough distance to analyze the phenomenon (Bowers, 1988). I am approaching this study with a constructivist perspective. Multiple realities are believed to be present related to any given phenomenon because an individual’s reality is constructed through the subjective meaning of his/her personal experience. However, there are many shared meanings within cultures that create some congruency among similar experiences.

I also recognize that I have preconceived ideas about maternal meaning of neonatal IVH that have been formulated through the experience of working as a NICU nurse and a neurosurgical nurse practitioner for the previous 17 years. I have spent a great deal of time working with families who are dealing with the repercussions of preterm birth and IVH. This has shaped my beliefs regarding the dramatic long-term impact this diagnosis may cause. However, I have not had the opportunity to work with families whose children have not required this type of long-term care. I hear the stories of “miracle babies”, but this is not my daily reality. It is important to recognize my own beliefs about the course of IVH, as it could impact data gathering, analysis, and interpretation.

In order to process these experiences and how they have shaped my work, I used journaling as a method to bring invisible assumptions to light. This helped me to
understand the preconceived thoughts I brought to the analysis. I also worked with a multidisciplinary research team in an effort to ensure that analysis remained grounded in the data. I fully recognize that the explanatory model created through this project is a construction of reality, produced from the interaction between the participants and myself.

**Section 3: Process of Investigation**

**Human Subjects**

Institutional Review Board (IRB) approval was obtained through the University of Florida IRB-03 and Wolfson Children’s Hospital (Appendix A) in Jacksonville, Florida. Participants were informed both verbally and in writing that their participation was strictly voluntary. They were also informed that no identifiable data would be released in publications or reports, including reports made to the funding agency, Rehabilitation Nurses Foundation (Appendix B). All identifying information, such as contact information and informed consent, was kept separate from the interview data in a secured area per IRB protocol. Informed consent was explained and obtained prior to participation in the study (Appendix C). This consent allows for future contact for follow-up interviews. Participants were also told that there was no penalty for withdrawing from the study prior to completion. Risks to participants were minimal; however, it is recognized that participating in discussions related to the sensitive issues of preterm birth and its possible complications may pose psychological or emotional distress to mothers. The mothers were informed that they could choose not to answer questions during the interview process. In instances where the mother appeared distressed during or after the interview, information regarding counseling was provided (Appendix D). Participants were given a gift card valued at $20 for their participation at the
conclusion of each interview. All team members completed Health Insurance Portability and Accountability Act training. Dr. Barbara Lutz, dissertation chairperson, was named as the Principal Investigator and oversaw the safety of subjects and reviewed analyzed data.

**Sample and Setting**

Purposive sampling was used to identify mothers of infants who were (a) hospitalized in level III neonatal intensive care units in two institutions in northeast Florida and (b) had been diagnosed with any grade of intraventricular hemorrhage. Inclusion of participants from two hospital units allowed greater population diversity. After initial purposive sampling, theoretical sampling was used to guide further data collection specifically related to the emerging categories. This type of purposive sampling is based on the iterative process of data collecting, coding, analysis, and planning in grounded theory (Glaser & Strauss, 1967). For example, after interview three, analysis revealed that mothers who had given birth recently were still swirling from all that had happened to them in the preceding week or two. It was very difficult for them to discuss IVH as they had not had adequate time to process all that was happening. Therefore, a decision was made to recruit mothers who were further along in this process. Subsequent mothers were interviewed when their infants were three to four months of age. Theoretical sampling was also utilized in the decision to recruit a mother late in the study whose baby required treatment of posthemorrhagic hydrocephalus through placement of ventriculoperitoneal shunt. This was believed to be important because this type of invasive treatment may alter perceptions regarding IVH. Previous to this mother, only one mother of an infant who required this type of treatment had been interviewed.
Sampling concluded when categories reached saturation. This was determined by Glaser’s (2001) definition of saturation in which addition of data reveals no new properties of the patterns that have emerged. The constant comparative method with the use of memo writing provided guidance in determining saturation of a category. This was discussed and verified with a multidisciplinary research team consisting of qualitative researchers including several with expertise in GT methodology, and graduate students. In this study, categories appeared to be nearing saturation after a total of thirteen interviews were completed. These interviews consisted of nine first interviews and four second interviews. However, links between the categories had not been fully established. Two additional mothers had already been recruited at this time, but had not yet completed the interview. One additional mother was added for the purpose of theoretical sampling as previously described. Analysis of these three interviews did not reveal any new categories or dimensions within established categories, which helped to establish saturation. Linkages were better delineated through ongoing analysis of all the data.

**Data Gathering**

Staff members caring for patients in the NICUs were asked to identify infants diagnosed with IVH based upon a radiologist’s reading of a head ultrasound. They provided the mothers with the study flyer (Appendix E) that briefly explained the purpose of the study. If the mother wanted to be contacted by the researcher, she would fill in her contact information on the second page and sign it. This was not an informed consent and the mothers were only giving permission to be contacted by the researcher. Mothers were eligible to participate in the study if they gave permission to be contacted by the researcher, spoke English, and their infant was both hospitalized in
the neonatal intensive care unit and diagnosed with any grade of intraventricular hemorrhage. If all criteria were met, the mother was invited to participate in the study and informed consent was obtained by the researcher prior to the interview. Flyers were left at the bedside for sixteen mothers. One mother stated that she was not interested in participating. Two mothers were not given the form or chose not to fill it out and leave it at the bedside. One mother signed the form and verbally agreed to participate; but never scheduled the interview. Subsequently, twelve mothers were interviewed; nine of whom completed the second interview.

After obtaining informed consent, data were collected through digitally recorded in-depth semi-structured individual interviews lasting one to one and a half hours. Interviews were transcribed verbatim by a professional transcriptionist. After digital recordings were downloaded as audio files to a password protected computer, recordings were erased. Audio files were erased once data analysis was completed. All transcriptions were checked for accuracy by listening to the interviews and confirming the transcribed data. Any identifying information, such as names, was deleted. A support person was present if the mother so desired; however, only data collected from the mother were included in the analysis.

The first interview was conducted when the infant was hospitalized in the NICU, with one exception of an interview completed two days after the baby was discharged home. This variation in procedure occurred because the baby was discharged home several weeks earlier than expected. Initial interview questions (Appendix F) were open-ended and loosely structured around Kleinman’s (1988) explanatory model framework to elicit the meaning of an illness. Follow up questions and probes were
used to gain more in-depth insight into the mothers’ understanding, expectations, and needs. The initial interview guide was modified after interview four was completed. After analysis of the first four interviews was completed, it was noted that the mothers were asked about IVH early in the interview. Therefore, it was decided to ask the questions more broadly to learn how the mothers would include IVH while recalling the experience (Appendix G). These questions allowed for discovery of how participants perceived the phenomena without imposing the researcher’s ideas regarding the situation. Each interview session was concluded by asking the mothers to complete a demographic form (Appendix H). All the mothers agreed to complete the form. The mothers were reminded that they would receive a request for a second interview within three to six months of the infant’s discharge. A second interview was then conducted within six months of the infant being discharged home. Again, interview questions (Appendix I) were open-ended and loosely structured with follow up questions and probes being used to gain further insight. This interview focused on the mothers’ evolving understanding of the implications of IVH. The mothers were given a $20 Visa gift card at the conclusion of each interview. Field notes recorded at the conclusion of each interview were also transcribed and included in data analysis. An example of a field note is included in Appendix J.

**Data Analysis**

Transcribed data were entered into NVivo qualitative data management software. Identifying information had been previously removed. Interviews were assigned a numeric value for identification purposes. Only the researcher had access to identifying information linking transcribed interview data to the participant. This was destroyed at the conclusion of the study. Information learned in the study may be presented and
published; however, no identifying information will be included in the dissemination of findings.

Data analysis began with transcription verification by listening to the audio recordings and confirming the transcription documents. This also served the purpose of thinking about the interview in its entirety prior to beginning line by line in vivo coding. I felt that it was important to understand each story prior to deconstructing into codes. Line by line coding for each interview was initially performed on paper so that detailed coding could be performed without moving too quickly into constant comparison and categories. Then each interview was entered into NVivo and coded within nodes. An example of the early NVivo coding structure is illustrated in Figure 3-5. As coding progressed, the coding structure was adjusted to reflect emerging categories.

Initially, three interviews were conducted and analyzed beginning with line-by-line in vivo coding. There were no predetermined coding categories. This ensured that the researcher was open to theoretical possibilities within the data. It was immediately apparent that neonatal IVH was one component of the very complex phenomenon of preterm birth. Therefore, the focus shifted from understanding IVH to understanding the preterm birth experience and how IVH was situated within it. This process was documented through memo writing. Subsequently, the research questions were revised to reflect this shift (Glaser, 1978; Glaser & Strauss, 1967; Bowers, 1988; Chivotti & Piran, 2003). The original research questions were developed from my professional experience and review of the literature (Appendix K). Early analysis resulted in a revision of these to the final questions presented in chapters one and four, which were more specific to the experience from the maternal perspective.
Data analysis utilizing dimensional analysis (DA) line-by-line coding method based on the coding procedures set forth by Strauss (1987), Schatzman (1991), and Strauss and Corbin (1998) continued as data more were collected. As previously described, DA is a systematic method for analyzing and comparing text or narrative data in a grounded theory study to understand how study participants perceive a particular phenomenon, such as IVH, and its consequences, and how perspectives vary within and across contexts (Bowers & Schatzman, 2009; Schatzman, 1991). In this study, the attributes or dimensions central to understanding the preterm birth experience and IVH were identified after initial coding occurred. As these dimensions were amassed through focused coding, comparisons were continually made within and across narratives. A card sort was conducted to help delineate how the dimensions fit into broad categories. This analysis technique is performed by writing dimensions onto note cards and sorting them into categories. This facilitates linking data back together in conceptual relationships after being fractured during coding. As data gathering, coding and comparison progressed iteratively, several dimensions were tested as the central perspective before finding the best fit (Appendix L). Axial and theoretical coding facilitated categorizing the remaining dimensions into the four theoretical domains of context, conditions, processes, and consequences (Figure 3-6) from which the final explanatory model was developed (Bowers & Schatzman; Schatzman). This was an ongoing process with multiple iterations (Figure 3-7) prior to the acceptance of the final model.

Memo writing was used extensively throughout the research process to record methodological decision-making and theory development (Appendix M). Initially memos
were used to record ideas about specific codes. Ideas about how the codes were defined and what they meant were recorded. Later, the memos were used to categorize dimensions and process possible links (Appendix N). The memos documented decisions regarding sampling, questioning, coding, category development, concept emergence, and relationships (Appendix O). Memo writing is a critical part of the analytical process because it helps to track methodological decisions and theoretical renderings of the data throughout the research process. Memos and diagrams were also used to describe connections among concepts and advance the research process by revealing areas that required further development (Charmaz, 2006). The multiple iterations of this process were also documented through memo writing and diagramming.

**Section 4: Scientific Rigor**

Guba and Lincoln (1989) have developed criteria by which to judge the trustworthiness of qualitative research. They have labeled these criteria as “parallel” with the intention that they parallel criteria used to judge the conventional paradigm (Guba & Lincoln, 1989). Traditional tests of rigor include internal validity, external validity, reliability, and objectivity. Guba and Lincoln’s (1989) criteria include credibility, transferability, dependability, and confirmability. These techniques were used to ensure the trustworthiness of the qualitative research implemented in this study. Although, alternative approaches to evaluating constructivist approaches are presented by Guba and Lincoln, as well as others, the parallel paradigm was implemented in this study.

**Credibility**

According to Guba and Lincoln (1989), credibility is parallel to internal validity and is essential in establishing trustworthiness. Credibility of the study was established by
employing multiple techniques including utilization of well-established research methods, prolonged engagement with the data (22 months), persistent observation, peer debriefing, negative case analysis, progressive subjectivity, and member checks as described by Guba and Lincoln. Purposive sampling is a technique utilized in grounded theory to recruit participants who match broad, but specified research criteria. During recruitment, all eligible participants were invited to participate. This ensured that participants were not selectively chosen. I immersed myself within the environment of the neonatal intensive care unit through ongoing observations, recognizing that previous experience in this setting may have affected my perceptions. Peer debriefing was done in the multidisciplinary qualitative data group, as well as with other graduate students conducting grounded theory studies. Negative cases were discussed in these forums also. Progressive subjectivity was captured through memo writing. Memos tracked the developing model and show progression of ideas. Follow-up interviews were conducted with nine mothers who clarified issues and filled in gaps from the initial interviews. Member checking, which Guba and Lincoln consider essential, was performed with eight mothers in follow-up interviews to ensure that model development was consistent with their experience. The models were presented and explained to the mothers. Their feedback was incorporated into the final explanatory model. The final model was presented to four mothers who described it as fully capturing their experience.

**Transferability**

Transferability parallels external validity or generalizability (Guba & Lincoln, 1989). Ultimately, readers of the study will determine the appropriateness of transferring the findings to another context; however, the researcher is responsible for providing enough contextual description to make this possible (Shenton, 2004). In this study, thick
descriptions of the context in which the theory was developed are provided. Description of the sites, participants, data collection techniques, and data analysis are provided. This will allow other researchers to determine if the results are suitable for transfer to another context. This research was conducted with a very specific population; however, findings demonstrate a process that mothers utilize to develop strategies to help them deal with the uncertainty of their infants' illness. Complementary studies in other settings may demonstrate that the findings are transferable to other situations of childhood illness.

**Dependability**

Dependability is concerned with stability of data over time and parallels reliability (Guba & Lincoln, 1989). Dependability is related to study replication and is closely linked to credibility (Guba & Lincoln). Accurate descriptions of the processes utilized in the study are essential. Shifts in constructions are expected as the theory emerges; however, these shifts need to be documented and traceable (Guba & Lincoln, 1989). This can be achieved through a dependability audit that accurately documents the research steps. There must be enough detail that the study could be replicated using the same techniques; although, they will not necessarily provide the same results due to shifts in phenomena (Shenton, 2004). The dependability audit for this study is contained within the memo writing. Thorough memos were kept that illustrate the research process and changes made as the theory was developed.

**Confirmability**

Confirmability is parallel to the convention of objectivity (Guba & Lincoln, 1989). A multidisciplinary research group including a grounded theory methodologist, qualitative researchers, and doctoral students was assembled for the purposes of data analysis.
This ensured that the emerging theory remained grounded in the data and that discipline related viewpoints did not distort the analysis. Coding procedures, shifts in thinking, and model development were extensively discussed within the group (Appendix P). This group served as the forum for peer debriefing. Several negative cases were analyzed to determine possible alternative concepts and how shifting conditions may affect the experience. Again, an audit trail was established through memo writing. Journaling was used as a method to limit researcher influence of the findings by bringing visibility to assumptions, thoughts, and attitudes. The research method and utilization in this study was also investigated for strengths and weaknesses which are discussed in the following section.

**Strengths**

Neonatal intraventricular hemorrhage is a complex phenomenon that usually occurs in association with preterm birth. This event is deeply embedded within multifaceted social and cultural factors. Beliefs about life, autonomy, disabilities, and death may all be confronted within hours of delivery. Mothers may struggle to create meaning of their preterm birth that has occurred within a society that often holds them responsible for this event (Landsman, 2009; Massett et al., 2003). Subsequently, they are faced with a complication that is likely to have lifelong implications. Intraventricular hemorrhage can result in an immediate life-threatening event or manifest more subtly with few recognizable physical changes. Long-term implications are difficult to predict at the time of occurrence. Mothers attempting to create meaning of this event will likely confront a great deal of uncertainty and fear in regards to their infants’ survival and subsequent neurodevelopment. As conditions such as stability of the infant, transition home, and neurodevelopment change, perspectives of IVH are likely to evolve.
The study of this complex phenomenon can be fostered by the rigorous systematic processes utilized in grounded theory that were previously outlined. These processes help to ensure that theory is developed from the data; thus, the theory is a conceptual representation of the participant’s reality. Data gathering through in-depth interviews produced rich data that is context specific. In the early stages of research, the mothers’ explanatory model of IVH was the most beneficial in understanding her perceptions. However, later in the process, cultural and social dynamics needed to be explored more fully. The iterative process used in grounded theory was useful in determining which concepts associated with preterm birth and IVH needed to be further explored. Utilization of theoretical sampling facilitated a more complete understanding of the emerging concepts, allowing sampling to be adjusted in an effort to obtain more data about certain concepts. Using the constant comparative method, in-depth comparisons between interviews allowed conceptually rich knowledge to be produced.

Using the perspectives of symbolic interactionism and explanatory models, the maternal meaning of IVH was constructed using symbols that convey cultural and societal meaning. The symbolic meanings associated with technology, birth, knowledge, disability, and so on were explicated to form a more complete understanding of what was occurring in multiple dimensions. These meanings informed maternal actions. Recognition of symbolism and associated interactions created an understanding that is conceptually deeper than providing a rich description of the event, which is the ultimate objective of grounded theory.

**Limitations**

Limitations in grounded theory are associated with the researcher and the data, since these are the major components of the methodology. A researcher’s inexperience
can be a limitation in grounded theory. The researcher is the tool by which data are collected (Bowers, 1988). Data, as well as theoretical thinking may be affected by inexperience. Interviewing is a skill that requires development. Interviews performed early in a researcher's career may not elucidate data that advance the analysis to a more conceptual level. Theoretical thinking must also be cultivated in order to transform description into substantive theory. In order to limit the effect of researcher inexperience, the research team should be comprised of at least one member who is well versed in the methodology of grounded theory. Another challenge in grounded theory research is recognizing that researchers may bring assumptions to the analysis. It is important to prevent these assumptions from becoming a part of the interpretive reasoning of the conceptual framework. This can be achieved through the systematic analysis previously described (Strauss 1987; Schatzman, 1991).

Grounded theory produces conceptual theories that explicate social phenomenon from the perspective of the participant; however, the theories are context specific, limiting broader application. The perspective of neonatal intraventricular hemorrhage is likely to vary greatly in accordance with expectations of development. A six month old infant who is not meeting milestones may be perceived very differently from a ten-year-old child who is delayed. A substantive theory developed through data collected from mothers of infants may not be applicable to mothers of older children or those who have children with other disease processes.

**Discussion**

Neonatal intraventricular hemorrhage is a complication of prematurity that usually occurs within hours of birth. Many mothers are still struggling to create meaning of their preterm delivery when they are confronted with their child’s life threatening
complication. It is important to understand how mothers perceive intraventricular hemorrhage because their beliefs will directly affect how they incorporate the illness into their life. Studying the maternal perspective of neonatal IVH using grounded theory generated a theory utilizing symbolic interactionism and explanatory models as frameworks from which to understand the cultural beliefs that are held and shared among members of a society through social interaction. The explanatory model developed in this study can be a place to enter a “shared space” between healthcare providers and mothers when discussing neonatal intraventricular hemorrhage, treatment, and long-term consequences.

**Summary**

This chapter explained the methodological process used in this study to create the explanatory model Reframing Motherhood. The theoretical perspectives used to guide the study were discussed in detail. Their association with grounded theory was thoroughly explored. The historical roots of grounded theory, as well as its evolution were summarized. The constructivist grounded theory method and the rationale for using this method was explicated. The researcher’s experience and its potential to influence the research were outlined. The process of investigation of the study was thoroughly detailed, including the data analysis procedure. Scientific rigor, strengths, and weaknesses of the study were discussed. The following chapter illustrates the final explanatory model developed from the data.
Figure 3-1. Explanatory Model Framework. Adapted from: Kleinman, Eisenberg, & Good (1978).
**Explanatory Model Questions**

- What caused this problem to occur?
- Why did the problem occur at this time?
- What does the problem cause to happen?
- What is the severity and duration of the problem?
- What kind of treatment does this problem require?
- What do you hope the treatment accomplishes?
- What are the biggest problems that this illness has caused?
- What do you fear most about this problem?

Figure 3-2. Explanatory model questions. Adapted from: Kleinman, Eisenberg, & Good (1978).
Figure 3-3. Meaning and action from explanatory model and symbolic interactionism perspective. Adapted from Charon (1995).
Figure 3-4. Dimensional analysis explanatory matrix. Adapted from Schatzman, L. (1991).
Figure 3-5. NVivo coding structure.
Figure 3-6. Early model. Developing maternal understanding of IVH.
Figure 3-7. Revised model. Developing maternal understanding of IVH
CHAPTER 4
FINDINGS

The purpose of this study was to explore the process of becoming a mother to an infant who has experienced an intraventricular hemorrhage following preterm birth with the intent of understanding the meaning mothers attribute to IVH and how meaning is developed in order to construct a substantive theory that explains this complex process. This complex phenomenon can only be understood within the context of preterm birth, so this experience is also described. Section one of this chapter will describe the participants in the study. Section two will provide the findings of the research. The explanatory model developed from the data will serve as a framework to explicate the study findings.

Section 1: Description of the Sample

The sample for this study consisted of 12 mothers whose infants delivered preterm and subsequently developed neonatal IVH. All the mothers lived in northeast Florida and their infants had been hospitalized in a level III neonatal intensive care unit. In total, 21 interviews were conducted. Eleven initial interviews were conducted while the infant remained hospitalized. One interview was completed after the baby went home from the hospital because he was discharged much earlier than expected; therefore, a second interview was not completed. Nine mothers participated in the second interview. One mother was lost to follow-up. The last mother interviewed was recruited for the purpose of theoretical sampling late in the study; therefore, only one interview was completed. Four mothers chose to have the father of the baby present for at least one of the interviews. Comments made by the fathers during the interview were not analyzed. However, it was noted that on several occasions, these comments resulted
in the mother changing something that she had said previously or elaborating more about a particular subject. The mothers ranged in age from 19 to 36 years. Eight of the mothers were single, but all were in relationships with the father of the baby. Education levels were evenly distributed between the categories of high school degree or less, some college, and college degree. Two of the mothers did not provide a response regarding household income. One-third reported household incomes less than $25,000 annually. One mother reported a household income greater than $100,000 annually. Five of the women were first time mothers. Ten deliveries occurred between 24 and 26 gestational weeks. Of the 12 infants, 8 had a severe intraventricular hemorrhage. Demographic data is represented in Table 4-1. The following section is a brief description of each mother and her experience. This personal account allows the reader to know who these mothers are within the context of their experience.

**Mother One**

The first mother interviewed for the study was 30 years of age and had two children. Her older child, an 8-year-old daughter, was also born preterm at 34 weeks gestation. She iterated many times how different this experience was compared to her daughter’s hospitalization after birth. She had experienced one pregnancy loss. She is single, but lives with the father of the baby. She dropped out of high school and is not working at this time. The household income is less than $25,000 per year.

The mother was on bed rest for approximately two weeks prior to delivery. She developed a urinary tract infection that caused her to go into preterm labor. She was evaluated by her obstetrician who believed her to be in labor and sent her to the hospital. She was evaluated and released home. Later that night she felt her bag of
water in her vagina and returned to the hospital. She then was transported by ambulance 45 minutes to a hospital with a level III NICU where she delivered. Her baby was born at 25 weeks gestation and had a severe IVH. He subsequently developed hydrocephalus and required insertion of a ventriculoperitoneal shunt for treatment. She was interviewed twice. The first interview took place when her baby was seven weeks of age and the second interview occurred seven months after discharge. This interview was not conducted within six of months of discharge as described in the process of investigation because the baby had several hospitalizations after his initial discharge from the NICU. At the time of the second interview, the baby had undergone three surgeries related to his ventriculoperitoneal shunt. There was a stark contrast in the mother between the first and second interview. During the first interview, she appeared almost bubbly. She laughed often, which could have been because she was nervous, but overall, she was very positive. She described being told at two days of age that the baby possibly had a brain bleed. An ultrasound revealed that the baby had bilateral severe hemorrhages. The mother stated that she “kinda ignored it, like what does that mean . . . .” Her understanding increased after being shown the head ultrasound images. The second interview occurred approximately two weeks after the third ventriculoperitoneal shunt revision. During this interview, she cried several times. She talked openly about how hard this experience had been and how at the outset she had no idea how difficult this process would be. She spoke candidly about depression as reflected in this quote.

Because I cannot do it by myself, especially with, um, me doing this depression thing and trying to get over it. If I don’t have my support, how am I gonna get over it, you know and succeed as a mom, you know.

At the end of the interview, counseling resources were provided to the mother.
Mother Two

The second mother interviewed for the study was 20 years of age and had two children. Her daughter was 10 months of age when her second child was born. She is single, but lives with the father of her children. She had completed high school and was attending college. She does not work outside of the home. Her household income is less than $25,000 per year.

She visited the doctor for the first time in this pregnancy at 22 weeks gestation. Just after this time, she discovered she was having twins, but one of the babies had died in utero. She subsequently went into spontaneous labor at 27 weeks gestation. She recalled not really knowing why she was having so much pain and attributed it to not drinking or resting enough. However, the pain increased so she went to the emergency department. Attempts to stop her labor were futile and she delivered two and half hours after her arrival. She was unable to recall any information received during this time. The following is a quote of the mother describing her delivery experience.

When he was delivered it was so quick, quick, the doctor, they couldn’t, like they didn’t have all their stuff because they thought I was pushing. They was telling me to stop pushing. I was like I’m not pushing. The baby’s coming on its own, so everything was like so quick.

The initial interview was conducted at the hospital one week after her delivery. The baby had a unilateral severe IVH. She described in the following quote being told about IVH the day she was being discharged from the hospital approximately 36 to 48 hours after delivery.

Many premature babies have it. And it’s something to worry about, but they, um, going to look over it and making sure that it don’t get any worse though than what it is.
She had not received any further information at the time of the interview so she was very unsure of cause or implications. She stated that a nurse was going to get her a book, but there was construction in the unit and she was not able to obtain it at that time. By the end of the interview, the mother was questioning me about IVH. It seemed the interview had created a sense of importance of the issue to the mother.

The second interview was conducted in her home when the baby was six months of age. The older sister, now one year of age, was also present for the interview. The mother described the baby’s course in the NICU which was complicated by multiple infections and feeding difficulties, as well as IVH. He was discharged around two months of age. She described him as “progressing very well”.

**Mother Three**

The third mother interviewed was 19 years old and lived with her parents. When she found out she was pregnant, she was afraid of telling her parents. She completed high school and currently did not work outside of her home.

The initial interview was conducted at her parent’s home when the baby was one week of age. This mother learned she was pregnant at four months gestation. At her initial doctor’s visit, she was already two centimeters dilated. She was put on bed rest and a cerclage was recommended. She was afraid to have the surgery because she thought it could lead to a miscarriage. She didn’t believe that the incompetent cervix would lead to a preterm birth.

So, it was like, you know, they telling about oh, you could have your baby premature and I didn’t think I was gonna have her premature but I did.

My doctor came in and she was like we gotta get you to the labor and delivery. You’re delivering this baby now and it all happened so fast. Like, I didn’t think I was gonna like have the baby that day.
At 25 weeks gestation, she woke up in the middle of the night in severe pain and bleeding. Rescue took her to the nearest hospital. She was then taken to the hospital via ambulance with a level III NICU because they “could save the baby”. She delivered vaginally soon after her arrival. At the time of the first interview, she had known about the IVH for two days. It was a unilateral mild bleed. She wasn’t worried about the bleeding and felt like the baby was doing well. She was told it was mild and “nothing to worry about now”. Her younger sister, who is eight years younger, was also born premature. She often used her sister as a point of reference when discussing the outcome possibilities. Her mother, the baby’s grandmother, was her biggest source of support. She relied on her for information regarding the baby. The second interview was also conducted at her parent’s home when the baby was seven months of age due to rescheduling of the interview. The baby was scheduled for a follow up cranial magnetic resonance imaging (MRI) for evaluation of the hemorrhage. The mother felt like this imaging would identify if the blood had absorbed and if so, there would be nothing to worry about.

**Mother Four**

The fourth mother interviewed was 22 years of age and this was her first baby. She was single and had not finished high school. She didn’t work outside of the home. Her household income is less than $25,000 per year. Her baby was born at 28 weeks gestation and had a unilateral mild IVH.

The initial interview was conducted when the baby was two months of age. The mother started experiencing vaginal bleeding at 27 weeks gestation and was admitted to the hospital where she remained on bedrest until the baby was born via vaginal
delivery one week later. During the week of hospitalization, she recalled someone from the NICU coming to discuss with her possible complications the baby may have.

They were talking to me about like premature babies could have IVH, blood in their brain. They all could they could have ROP [retinopathy of prematurity], you know, with their eyes. Which is the um, it get attached from the eyelid. Eyelid something like that. And what else? He was just talking about like his lungs not being fully develop. Um, NEC [necrotizing enterocolitis], what my son had. You could be feeding him, but as you were feeding him or whatever, I guess-I don’t know if they’re not tolerating it, but basically they stomach get-their stomach get kinda bigger. And that means that they had a hole in their intestines or something like that. And it’s a it’s a lot of things you have to watch out, but the NEC is like real common for a premature baby. And that’s what he had. That’s what he had. He had the NEC.

The baby had been transferred from one level III NICU to the other level III NICU because he required surgery for NEC. She learned about the baby’s IVH prior to the transfer. She stated at that time she felt as though things couldn’t get worse. This was the only mother to mention the possibly of stopping treatment, but decided against this after speaking with the neonatologist. Although the baby had a very difficult course, she believed the blood would “dissolve” and the baby would not have brain damage because the bleed had not been severe. The second interview was not conducted with the mother because her phone was disconnected and she had not provided alternative contact information.

**Mother Five**

The fifth mother to be interviewed only completed one of the two interviews because the baby had been discharged home at the time of the first interview. She stated that she was shocked because he had been discharged over a month earlier than she had expected. She was 36 years old and had a bachelor’s degree. She worked full-time as a customer care representative. Her household income is $26,000
to $50,000 per year. She has four children, all of who were born earlier than full-term. She had experienced two previous pregnancy loses.

The baby was born via cesarean section after a one week hospitalization and bedrest. The mother woke up one morning and had vaginal bleeding. She went to the hospital and discovered she was three centimeters dilated. Prior to delivery, she did not recall any neonatology staff coming to talk to her about the baby. She thought that it could be because she had experienced preterm births in the past, but she pointed out that this was different because her other children had not been this early. It was 48 hours after the delivery before she was able to see the baby. She described being frightened and feeling guilty for having a baby at her age. One evening she was in the NICU and one of the staff members was getting updates on the babies. The staff member mentioned IVH to the mother. She was shocked because there was a two week delay between when the scan was performed and when she received the results. She was provided reassurance in that it was only a grade II IVH and they would be worried if it was a grade III or grade IV IVH. There was a discussion of possible complications that included blindness and cerebral palsy. The following is a quote from the mother describing this encounter.

Um, she-what did she say? Um, what did she say? Well, retardation or um, I'm trying to think. Blindness. Um, what else did she say? I'm trying to think. Oh, she mentioned cerebral palsy, but I didn't go online and read that myself. All that – you know, she did go over some of it with me. But I was just so in shock that night. I was like, "Let me go online and look it up myself and better understand it myself."

At the time of the interview, the mom felt as though the baby was doing well because "technically he was not suppose to be here yet".
Mother Six

The sixth mother who participated in the study was interviewed while “rooming in” in the NICU on the eve of discharge. The parents spent the night in the room caring for the baby prior to discharge home. The mother was 29 years old and single. She lived with the father of the baby. Her household income is $26,000 to $50,000 per year. This was her third child. She had previously experienced two pregnancy losses. She attended graduate school and was a teacher, although not currently employed.

This mother experienced high blood pressure throughout her pregnancy so the baby was smaller than expected by one to three weeks. She had been hospitalized several times during her pregnancy. The final hospitalization occurred 12 days prior to her delivery. The following is a quote about the day the baby was born.

So they gave me a choice, they said you can try and wait, and not have your baby, and then your liver’s gonna fail and you’re gonna have to have emergency liver surgery. And then you’re going to have to have a C-section, have your baby early, still. OR we can take your baby, save you the other surgery and, you know, take your chances with what happens. So we decided that since it was inevitable either way, that we would go ahead and just have her.

The neonatologist came and stood by me as I’m being drugged and cut open, and he told me all of the things that could go wrong. And you know, he was the one who was saying don’t expect her to live because he’s just piling on us this list of things that’s a mile long.

The baby had many complications during her stay in the NICU. During a discussion about her feeding difficulties, it was mentioned that she had IVH, but it was significant enough to cause the feeding problems. The mother responded “You know, you kinda forgot to tell me”. The second interview was conducted five months after discharge when the infant was nine months old. The baby had been hospitalized twice since the initial discharge for a fever and problems with the gastrostomy tube. After the first
rehospitalization, the baby had completely stopped taking any bottles and was getting all her feedings through the gastrostomy tube. The mother had other concerns about getting follow-up care, but stated that she could not afford all of the out of pocket expenses. She believes that the baby is making progress and developing at her own rate.

**Mother Seven**

This mother was 36 years old and described herself as a “type A personality”. She was married and had waited seven years to get pregnant. She worked as an attorney. Her household income is greater than $100,000 per year. This was her first pregnancy. The first interview was conducted when the baby was three months of age.

Early in the pregnancy, she had some bleeding which was checked several times by her obstetrician and a high risk obstetrician. She was reassured on several occasions that everything was progressing as expected. She went on to have a couple of episodes of urinary urgency that she thought may have been a urinary tract infection, but again, all the tests came back negative. She woke up in the morning after one of these incidents to find that her water had broken. Her husband drove her to the nearest hospital and they were preparing to transfer her, but the baby became distressed and they had to deliver him by cesarean section. The baby was immediately transferred to a hospital with a level III NICU and the mother stayed. The transport team briefly brought the baby to the mother’s bedside. This mother was very well informed and had already investigated hospitals and NICUs. She said she immediately knew that there would be many complications to face. “I was very aware week by week how the baby was progressing.” However, she never had imagined spontaneous rupture of membranes. She had been more worried about possibly getting in a car accident so her husband
bought a sport utility vehicle for her to drive. However, after the baby was born she struggled with self-blame.

Sorry, but you always want to blame yourself and think, you know, what if you know, I had, you know, I told my husband what if I had had you take me into the ER that Saturday? And what if I had done this?

The following day, her obstetrician released her from the hospital because the baby had become unstable and it was unclear if he would live much longer. Seeing her baby brought her a great deal of comfort.

Oh, it was amazing. I mean, very honestly, after I came out, everybody says I looked just a thousand times more relaxed and at peace, and as soon as he heard my voice he reacted to it.

And all I could-I mean, all I remember is just looking at him and just feeling so much love and seeing that he, you know-knowing that he heard, you know, my voice, and knowing that I was there for him, and I didn't even think about all the wires or anything else. It was just seeing my baby.

The mother knew at this time that there was a significant possibility of IVH because the baby's hemoglobin had dropped very low. The following is the mother recalling how the nurse had discussed IVH with her.

And so she was very kind in that she prepared me and just told me that, you know, here in the NICU they see babies with, you know, threes and fours that beat the odds statistically, and with therapy, and with everything else, and that sometimes you have a one, two that can end up being devastating, and you have a three, four, and the child does fine, and I know- I understand statistically. I am not in denial, but you know, she was just very reassuring basically, um, just talking to her and very compassionate.

The next day the mother was told that the baby had bilateral severe IVH. His course had many complications and through this time his parents became very strong advocates for his care.

The second interview was conducted when the baby was eight months of age and had been home for six months. The mother discussed how much it meant to bring
her baby home even though he continued to need oxygen and monitors. Although, she looked back at the time her baby spent in the NICU with fond memories. She attributed this to the relationships she had built with the “primary” nurses. These nurses agreed to care for her son whenever they worked so he had consistent care. The mother spoke of what a “huge investment” these nurses had made in her son. She felt they had taken the journey with and had believed in her son. It had been a scary course but these bonds had helped her through this time. Her baby had not developed hydrocephalus and yet she spoke of the long term effects of IVH. She knew that even though the blood had “resolved” that damage had been done. Now she had to do her part to give her son the best possible chance of helping her son “rewire”.

**Mother Eight**

This mother was 30 years old and married. This was her third baby. Her previous children had also been born early, but close to 40 weeks gestation. She has completed some college and works outside of the home in a daycare. Her household income is $26,000 to $50,000 per year.

The first interview was completed when the baby was almost two months old. Her husband was present for the interview. When she was 25 weeks pregnant, she woke up and discovered some vaginal bleeding. She went to the hospital believing that nothing was really wrong and discovered she was five centimeters dilated. She was in the hospital one week on bedrest and delivered by cesarean section. The mother discussed the rates of survival that she was provided prior to her delivery although the father disagreed with her depiction. The father’s comments were not analyzed as stated in the IRB protocol; however, it was noted that he believed the information that the mother provided was not accurate. Several days after delivery, the baby required
abdominal surgery due to necrotizing enterocolitis. He was transferred to the other level III NICU for treatment. He had a unilateral grade IV IVH. At the time of the interview, the mother was awaiting a meeting with the doctor to discuss the results of the latest ultrasound. At this time, she felt like it was more difficult to bond with her baby because of being in the NICU. The second interview was completed when the baby was seven months of age and had been home for four months. He came home around five weeks prior to his due date so the mother was not prepared as she believed he would likely be in the hospital for another month. She felt like once he came home that she was able to be his mom. The following is a quote from the mother describing the baby.

Right now, it’s just day to day. I mean, if a problem occurs in the long run, then there’s just another obstacle we’ll have to face. But right now, I mean, he is a normal child.

Mother Nine

The ninth mother interviewed was 25 years old and married. This is her first baby. She delivered at 26 weeks gestation secondary to a uterine fibroid tumor. The baby developed a unilateral severe IVH.

This mother was hospitalized at 25 weeks gestation for preterm labor. She was on strict bedrest and received steroids in anticipation of delivering the baby prematurely. She recalled a neonatologist describing possible complications the baby might experience. Intraventricular hemorrhage was one of the complications discussed and on the first head ultrasound, the baby was found to have IVH. The severity progressed from mild to severe by the second ultrasound. The following quote demonstrates this mother’s early understanding of IVH. “Ah, I think she was 28 weeks or so when we found out she was bleeding but it was nothing to worry about, they said. But, and then it got worse”.

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The second interview was conducted in the mother’s home when the baby was six months of age and had been home for three months. The father was present for a portion of this interview. At this time, the baby was awaiting MRI follow-up regarding the IVH. The mother believed the baby was progressing very well and felt this was verified by the physical therapist who reassured her that the baby was doing well. She was happy to get good news, as this was contrary to news received in the hospital. She stated that “when she was in the hospital we got no good news” and followed up by saying “I noticed that they wanna scare you a lot”. This mother believed that her baby’s outcome was better than the doctors had projected when she was in the hospital.

**Mother Ten**

This mother was 27 years old and married. She had completed some college. She stated that she worked in customer service, but is currently unemployed. Her household income is $26,000 to $50,000 per year. This is her second child.

The first interview was conducted when the baby was three months old. Her husband was present for the interview. The mother stated she began to have back pain about one month prior to her delivery. She was prescribed physical therapy and rest. One evening during dinner she began experiencing severe abdominal pain. She went to the hospital and was found to be six centimeters dilated. She delivered within the hour. She was unsure if anyone from the NICU talked to her prior to delivery and she would turn to her husband for clarification when she was unable to recall the events. I asked the mother if she recalled having conversations and she replied “I had to basically ask him everything afterwards”. She delivered at a hospital that did not have a level III NICU, so the baby was transferred soon after delivery. This mother was different in that she stated the she never worried that he wouldn’t survive.
I never did doubt whether he wasn’t going to survive or anything. I just was because he wasn’t like that bad off I probably was like is he fully developed, is his lungs okay, certain stuff like that. I guess with me being a mother I was just really tripping. I mean, it was very hard for me.

The second interview was conducted at the mother’s home when the baby was seven months old and had been home for three months. I asked her about her belief in the baby’s survival. She attributed it to faith. She has a tremendous faith in God and always believed that her baby would be protected. She talked pointedly about having conflicts with the neonatologist about this.

I never really cared about what they said. I mean, I know that they—I used to tell them that too, so me and Dr. H used to go back and forth a lot about that, but it was cool, and you know, she end up having to laugh about it.

Although this baby has a grade IV IVH, this mother continues to have tremendous faith in God and her son’s ability to overcome this complication.

**Mother Eleven**

Mother eleven is 29 years of age. She is single, but lives with the father of the baby. She has completed some college and works as a claims analyst. Her household income is $26,000 to $50,000 annually. This is her first pregnancy and it was planned.

The first interview was conducted in the hospital when the baby was four months old. This mother told me several times that this pregnancy was planned and how hard that was for her because she internalized a great deal of blame because she wanted “a baby to love.” She described having hyperemesis from the beginning of her pregnancy and she couldn’t work, but needed to continue caring for her disabled mother. At 24 weeks gestation, she noted some spotting and discomfort, so she went to get checked “to make sure that everything was fine”. She was five centimeters dilated and she
delivered that evening. She was surprised about how strong the baby appeared and was devastated when she was told about IVH.

Now, it was shocking to the nurse and probably to me, and then when I found out about the IVH that was devastating, a lot of depression, and crying, and not understanding…

This mother also had very strong faith and never doubted the survival of her infant. The second interview was conducted at the mother’s home when the baby was six months old and had been home for two months. The mother was actively participating in therapy with the baby and believed that he was progressing well based on his adjusted age. She states that babies usually “catch up” by their first birthday, so she thinks she will know by one year of age if there will be any lasting problems. She continued to express the guilt she feels related to his preterm birth.

I wanted a baby, that’s why it happened. If I hadn’t wanted a baby, it wouldn’t have happened.

She is very dedicated to being there for the baby and working with him. She tries to find a balance being his mom and acting as a therapist.

**Mother Twelve**

This mother is 20 years old and lives with her boyfriend. She has attended some college and currently works as a prep cook. Her household income is less than $25,000 per year. This was her first pregnancy and delivery experience.

The interview was conducted in the mother’s home when the baby was three months old. He remains hospitalized and is expected to have surgery to place a gastrostomy tube for feedings in four weeks. He was born via emergency cesarean delivery at 25 weeks gestation. The mother began experiencing cramping while working, but didn’t realize it could be preterm labor. During the night, the pain worsened
and her water broke. Her boyfriend took her to the hospital, but the labor could not be stopped because the baby was already delivering feet first. The mother woke up from anesthesia to hear that her baby was alive, but had to be transferred to a level III NICU. The transport team allowed the mother to briefly see the baby prior to leaving. The following morning the mother received a call from the neonatologist telling her that the baby had bleeding in his brain. The mother believed that the baby would not survive and left the hospital 24 hours after her emergency surgery so that she could see her son. Once at the NICU, the mother states that she was reassured by the nurse that this was a very common complication for preterm babies and the baby was okay. “Cause we really thought at that time, he wasn’t going to make it. But when we there, the nurse said, it is common and he is fine.” Receiving this information provided the mother with comfort. The mother talked fondly of a neonatologist that frequently updated her about the baby. She was very reassuring about the baby’s condition and his ability to be okay. Although this baby had a complicated NICU course, including insertion of a ventriculoperitoneal shunt, she maintained a very positive outlook regarding her baby.

In summary, twelve mothers participated in telling their stories surrounding the birth of their babies, their rocky course in the NICU, and their long awaited homecoming. These were intimate stories of motherhood and survival that provided a not only a recounting of the experience, but insight into the meaning. Through the study of these stories, the meaning of the experiences for these mothers can be captured and understood within the context in which it occurred. The following section describes the explanatory model developed from the perspective of the mother through analysis of their stories.
Section 2: Explanatory Model: Reframing Motherhood

An explanatory model was developed from the interview data, provided by the mothers who were previously described, that is a conceptual depiction of the process by which mothers develop meaning and understanding of neonatal IVH (Figure 4-1). The research question and study aims were addressed by situating the phenomenon of maternal meaning making expressly within the complexities of the preterm birth experience. Therefore, the model includes contextual and conditional dimensions of the experience that affect the process of meaning development. The following section, Reframing Motherhood, will provide an overview of the model. This is followed by a detailed discussion of each of the concepts and their linkages within the model. The section will conclude with a summation of how the model addressed the research question and aims.

Reframing Motherhood

Using dimensional analysis as previously described, the central perspective or dimension of the phenomenon under study was sought. Analysis revealed that reframing motherhood best conveyed the experience of maternal understanding and meaning development. Reframing motherhood describes how maternal thinking about motherhood shifts within the context of preterm birth and life threatening complications. When women become mothers, there is a social role expectation that is dependent upon cultural beliefs. These beliefs and expectations about the pregnancy, delivery, and baby are rapidly deconstructed once preterm delivery occurs. One mother stated, “All, everything that I planned, everything, all that went out the window when I was faced with this traumatic experience.” Subsequently, a process of reconstruction occurs with the result of mothering this baby differently than anticipated. This situation transpires
within a biomedical context in which the system seems to be in control. The goal is to avert death and technology is used extensively to achieve this. The mothers are spectators in the process, remaining unwavering in their faith and dedication while they fight feelings of self-blame. The mothers are living in a society that considers prenatal care protective against undesired pregnancy outcomes. Therefore, they often hold themselves responsible for choices during pregnancy that could have contributed to preterm birth. One mother stated, “I'm still, you know, beating myself up for it. . . . I feel like maybe I didn't drink enough water.” Although during the pregnancy, they never imagined having a preterm birth let alone all the subsequent complications. The babies are viewed as miracles remaining ever strong in adversity. This unexpected course into motherhood is fraught with uncertainty. It is explained as being on a roller coaster never knowing what is around the next turn or when the drop will occur, “It’s been a real roller coaster.” There are times of exhilaration and happiness that are tempered with shock and fear. There are emotions on top of emotions swirling around. At times it is hard to keep them under control, yet the mother must remain strong in the sight of her infant as the baby may sense negativity. “You can’t be like that in front of the baby. He feels what you feel.” Under all these conditions, the mother is learning what it means to mother her baby, this baby with IVH. This is not the baby who was expected, but this baby is loved immensely no matter the course or the outcome. “No matter how she turns out, I’m going to love her.” For these mothers, learning to mother is seen as a unique experience for each women, as each baby is different and each course has its own trajectory, so although the experiences may have some commonality, they are expressly different. In this process, the mothers gather information in multiple ways
from multiple sources. This information is then interpreted and incorporated and more information is gathered. It is intense as the mothers incorporate volumes of foreign information. This is an ongoing cycle and as it occurs the mothers begin to redefine hopes, reconstruct expectations, and live in the moment based on the meaning this information has for their lives. As mothers progress through this experience, they acknowledge that their life trajectory has been altered. This trajectory was not the one planned. It is full of uncertainty and yet, full of possibility.

Context

In constructivist grounded theory, analyses are social constructions that are contextually situated in time, place, culture, and situation (Charmaz, 2006). The context provides the boundaries of analysis and describes the situation in which the phenomenon under study is occurring (Kools et al., 1996). The following section contextually situates reframing motherhood by providing a narrative depiction of maternal experiences with biomedicine in the U.S. as it relates to viability and technology, with sociocultural beliefs and expectations related to pregnancy and motherhood, and with preterm birth complicated by IVH.

U.S. biomedicine

In the U.S., lower limit of gestational viability is generally viewed to be 23 to 24 weeks gestational age and a birth weight of 500 grams. At this size, life saving measures, such as endotracheal tubes, can be utilized. However, there are not specific guidelines that dictate management. As stated in an American Heart Association 2010 special report regarding neonatal resuscitation, “For neonates at the margins of viability or those with conditions which predict a high risk of mortality or morbidity, attitudes and
practice vary according to region and availability of resources” (Kattwinkel et al., p. e1407).

The mothers in this study were thrust into the world of biomedicine as signs of preterm delivery were imminent. They were admitted to hospitals, informed they would not leave until their babies were delivered, and then notified their babies would go on to spend at least their first months of life in a hospital. There were variations in the content of discussions regarding preterm delivery with healthcare providers that the mothers recalled. Several mothers did not recall any conversations about the care of the baby prior to delivery. Many mothers said they were told everything would be done to save the baby. Mother three even stated that the providers told her, “We are going to save your baby.” Only one mother in this study recounted being told that the neonate would be evaluated and a decision regarding resuscitation would be based on that assessment. For these mothers, there was no mention of making decisions about resuscitation. The baby was born and immediately was taken into the NICU where treatment began. The treatment included a vast array of technology, including ventilators, monitors, specialized beds, and so forth. Without this technology, saving these babies would not be possible. Many of the babies also required surgical interventions. The NICU course included complications and suffering for all the infants. The mothers spoke of powerlessness as they watched this situation unfold.

Nothing I can do. I just have to watch her being in there and suffer and—but she never showed the suffering. You could see it a little bit, but—like she would cry, but you wouldn’t know, like uh, sometimes it’d make me upset, like, I can’t do anything. I can’t touch her.

Yet, all the mothers were thankful for the medical care that their infants had received. Nursing care was frequently mentioned by the mothers as being a positive part of the
experience. They appreciated the care provided, the conversations had, and the reassurance they received from the nurses. The nurses supported the mothers during the up and downs of their NICU stay.

I’d say the biggest support group for us is through the nurses and that parents really need to realize that the nurses are these baby’s lifelines. They’re the ones who know the babies, who are looking at them every single day, who are going to be with your child the most, and um, that’s definitely been a huge comfort.

The mothers knew that their babies would not have survived without the staff and technology of the NICU. Many of the mothers were not bothered by the technology surrounding their babies and spoke of “just seeing the baby.” However, for some of the mothers “wires and connections” frightened them and made it difficult to hold and care for the baby. Regardless of their perceptions of the technology in the NICU, it was important for the mothers to be physically close to their babies. Although thankful for this environment that had allowed their babies to survive, all the mothers spoke of wanting to leave the NICU behind and take their babies home. These represented incorporation of the baby into the family. Many mothers described going home as being able to put the situation behind them by leaving the ups and downs of the NICU in the past. As one mother said, “I just wanna forget it, personally, um this journey.” In the context of going home, there was little discussion of the possible long-term effects of the NICU stay on the mothers or infants.

Once home, the mothers primarily utilized the medical system to ensure that everything was going okay with the babies.

And he just went and seen a neurosurgeon, just to make sure everything was okay, do a follow-up, so there, they confirmed everything was fine. At this point, we’re gonna keep monitoring and make sure there is not swelling or anything, so right now, we’re okay.
Primary care services were frequently used as routine evaluations for how the baby was progressing as well as immunizations. Most of the infants had undergone evaluations for therapies such as occupational, physical, and speech. However, not all of the infants were currently enrolled in therapy services due to lack of an appointment being given or the services were deemed not necessary based on the initial evaluation. Therapy services were often described in terms of reassurance that the baby was progressing as expected.

Yep, and she says every other Monday, cause she’s doing so good for a preemie, and they’re surprised, because a lot of preemies are really slow. But right now, she’s mostly a four month old, so they go by that. And they say that she does everything that she’s supposed to be doing, so she’s doing good.

This mother was referring to adjusting the age of the infant to account for the time she was born early. For example, a child that is born three months early is evaluated as being three months younger than her chronologic age. Based on adjusted age, this infant may not be exhibiting delays. Mothers are very hopeful that utilization of therapy will help the infant “catch-up” in their development. They exhibited a very strong belief in the power of therapy to help the infant and also teach themselves to provide care to the infants that will help them progress.

He’s qualified for Early Steps. So I’m so excited...because they can teach me something that I can look for or I can do with him or I’m with him all day, you know. I love playing with him, you know. And if I can do something to make him more, to do more things, I will do it. So I feel like they can tell me or give me some kind, kind of techniques, or they can say, hey, you know, he’s doing very well. This is what he’s, you know. The sky is the limit over there. Everybody talks about how great they are. And I’m just really excited to get him in that program.
Mothers wanted to be involved with their infants’ care and desired to contribute to their progress. This helped the mothers to gain control over a situation in which they have felt powerless.

However, biomedicine was also utilized when complications arose. One infant had several hospitalizations and three surgeries subsequent to his discharge from the NICU. This mother compared the experience in the pediatric unit to the NICU care. She felt it was difficult to be in the pediatric unit because the level and intensity of care was less than her experience in the NICU. The NICU seemed to create an expectation of care that was deemed as different and possibly, inferior, on a pediatric ward. For this mother, her roller coaster journey did not end with the NICU discharge as she had hoped.

The biomedical system was experienced for these mothers in unanticipated ways. Based on their sociocultural beliefs, they expected their pregnancy and delivery to happen very differently. The following section discusses the sociocultural beliefs of the mothers and how this influenced their experience.

**Sociocultural beliefs**

Pregnancy and childbirth are immersed within cultural traditions and expectations. In the U.S., prenatal care has a prominent role within the gestational period. All women in this study participated in prenatal care, although to varying degrees. Some were given specific recommendations related to the avoidance of preterm delivery, while others were provided reassurance that the pregnancy was progressing as expected. Even mothers who were told about the possibility of preterm birth did not believe that it would actually occur. All expected longer gestational periods than they actually experienced. Mothers who had previously experienced late preterm births were
surprised about delivering so early and continually expressed how different the experiences were. This mother is comparing her daughter born at 34 weeks gestation to her son born at 25 weeks gestation.

Because you have to understand, like I had a 34 weeker and this is a 25 weeker. It’s a completely, big difference. And I wasn’t, honestly, I wasn’t prepared to see a small, limp, itty-bitty thing. I wasn’t prepared to see my daughter that size, but he was born 1 pound, 7 ounce, so of course. You know he didn’t look like a baby. And nobody really told me that.

Although this mother had previously delivered early and had experienced signs of preterm labor with this pregnancy, she never thought this baby would be born so early and did not feel prepared for the experience.

Once these mothers delivered early, many began questioning why this had happened. Often they looked within themselves for the answer. They questioned decisions they had made and looked for things they could have done differently. This resulted in feelings of self-blame or maternal blame. Only one of the mothers felt that her healthcare providers should have dealt with the situation differently, and even she expressed feelings of maternal blame. The mothers clearly felt responsible for the health and well-being of their babies even before they were born.

Cause I really think that all his problems, him being born early and the problems he had was because of me. They kept telling me it was my cervix, but just, I was working so much, and I cook. So I’m on my feet all day.

So I was like, you know, I was kind of upset because me, one is my age, you know, and I shouldn’t get pregnant again because of my complications. So I felt guilty.

Sorry, but you always want to blame yourself and think, you know, what if, you know, I told my husband, what if I had had you take me into the ER that Saturday? And what if I had done this? . . . I mean, sometimes I just struggled with, again, the fact that what, did I do something in my pregnancy? Did something, did something cause this?
The blame sometimes was believed to be projected by others judging the mothers. One mother even spoke of the preterm birth as if it were a punishment for something that she had done wrong.

Cause you know how some moms get those looks like they think I did, was on drugs, or if I was on this. I’m like, “No, I had an illness that I did not know about that made her came.

God, please. Jesus, please. Help me God. I know Jesus, whatever I did wrong, God and Jesus, please forgive me for all my sins.

The mothers in this study spoke of cultural rituals or rites of passage related to pregnancy that were important to them. These included, but were not limited to, an enlarging abdomen, feeling the baby move, maternity photographs, baby showers, and homecomings. Many had specific plans related to these events. They expressed sadness about missing these experiences. Some of the mothers had a very strong response to this and described feeling robbed or cheated of their expected pregnancy and birth experience.

Oh, I just feel cheated. Like, you know, a pregnancy is like supposed to be—not enjoyable, but like you’re supposed—you’re – you’re watching your body grow outside, you know. Look in the mirror, taking pictures of your stomach, you know. I didn’t get all that. I barely got to feel a kick, you know, so—I feel him kick all the time now, but-- you know, it’s just not the same. Right. You know, all my friends are—well, just had babies. And they’re just like oh, you know, I’m so tired of him kickin’. I – I cannot get enough of it, you know. So I feel cheated, you know. I don’t—I didn’t have a normal baby shower, you know, the normal games, you know. I didn’t get the pregnancy pictures that I wanted, you know. I just got completely cheated. I mean, I felt like everything was a rush, even down to the day that he left—he came home.

This mother went on to talk more about being robbed of her experience. This sentiment was repeated many times by many mothers. From some, the actual experience at the hospital was very difficult as they could not see or spend time with their newborns.
Especially—when I was in the hospital, I heard next door—he was already gone, but I heard next door—I guess she’d just had the baby, cause I heard the baby cry. And hearing that, I just started crying cause I felt like, my child wasn’t here. He’s been taken away from me to another hospital. I knew he needed more treatment, but still. I just—he wasn’t there with me. Just know that—well. I as happy for her cause her child was there with her, but mine wasn’t, and I just started crying. I thought, it’s not fair.

Going home was celebrated, although differently than expected. Many had parties or baby showers once the baby was discharged from the NICU. They were thankful for these celebrations, yet continued feeling the loss of their expected experience.

Preterm birth and subsequent complications were viewed by mothers as a significant loss of expectations. This created a great deal of emotional turmoil, especially guilt. They expressed realizing on an intellectual level that they could not prevent the preterm birth; however, that knowledge did not alleviate the guilt they had about delivering early and the complications that followed.

**Preterm birth complicated by neonatal intraventricular hemorrhage**

All mothers in this study shared the experience of having a pregnancy that ended much sooner than expected. These mothers delivered their infants 12 to 16 weeks earlier than they had anticipated. Most mothers interviewed never imagined having a preterm birth while they were pregnant. Even the mothers who experienced symptoms associated with preterm birth never really thought of their babies being born early. Three mothers who participated in the study had been placed on bed rest at home for several weeks prior to delivery. One of these mothers described going to the hospital because of light vaginal bleeding. It was determined that she had an infection that was treated with antibiotics and bed rest. The mother describes her response when being told she could possibly deliver early.
And it’s something that, you know, you get. Just something I didn’t catch and, of course, I take baths every day, because I was always in, you know, my back always hurt. And so I think I got it from that, and they put me on bed rest because they did a swab saying that I could easily go in labor in two weeks. I thought they were lying. I really did.

Although she had stated her disbelief in the possibility of a preterm birth, she complied with the bed rest recommendation. Ironically, on the day she delivered, she had been to the doctor to determine if she could end the prescribed bed rest. Another mother closely monitored her pregnancy week by week with a pregnancy guide. She knew each milestone her baby was achieving in utero and yet, she never thought about spontaneous rupture of membranes.

I mean, you name it, I pretty much knew for what - the one thing that I had never researched before was preterm premature rupture of membranes, the one thing that happened to me. I never even fathomed my water just breaking out of the blue.

Regardless of the symptom that led the mothers to seek medical help, all mothers expressed shock at the news their baby would be delivered so early. Several mothers stated that they went to the hospital “just to make sure that everything was okay”.

As the mothers talked about their abrupt entry into motherhood, they struggled to recall the details. Several said that they did not remember anyone talking to them about the baby’s condition prior to delivery. Mothers who had chosen to have the father of the baby present during the interview often turned to the father for verification. They were attempting to remember details such as the chances of survival for their baby or possible complications the baby could experience that they had been given by healthcare providers around the time of the delivery. However, everything was happening so quickly that they were not able to process all that was occurring. Even mothers who had been in the hospital prior to delivery described the delivery as being
unexpected and rushed. Only one mother expressed being told that the baby may not be resuscitated.

So, then she was born. And she was very, very tiny, and you know, when they, when we were in the operating room, they were like, you really shouldn't expect her to live with, you know, they said, if she is moving and, and, you know, struggling, then we'll try and save her, but if she isn't responsive then we're not going to do anything. So, you, know, so you're advised. And I was like, no. No, we're not going to have that.

Mothers who were awake for their deliveries spoke of hearing the baby cry; some were able to see the baby for a moment prior to being taken into the NICU. For many mothers it was one to two days before they would see their babies again due to their own recovery. During this time, fathers or other family members would see the babies and bring news and pictures for the mothers. All the mothers stated that the babies were doing well at first and then became ill. This is not surprising as the first 24 hours for a neonate is considered the “honeymoon phase” as the baby often is stable during this phase. Mother three describes her baby as fine early in this phase.

They brought me back to my room and they admitted me in another room and right when they brought me to that room, they said you can come see her and I went to go see her. So, it was hard because I was scared because I had- they warned me about her, you know, not being able to make it. And when, you know, I got to see her and she’s doing fine.

Once the “honeymoon phase” ended, mothers described a myriad of complications their babies had experienced, including, but not limited to, respiratory distress, necrotizing enterocolitis, multiple infections, bradycardia, and IVH. (Figure 4-2). These complications were layered upon each other, as they occurred simultaneously. Most mothers recalled being told about IVH after a head ultrasound was performed, usually within the first week of life and sometimes within the first several days. These mothers were still recovering from the delivery and their infants were
struggling to survive. They were able to recall being told about many complications, but the focus of this time was on the infant’s survival.

I don’t, I wouldn’t care if my son was born retarded, you know, I’m being honest. That was the most important thing to me. Just that, that’s the only thing I was worried about with everything. Cause I wasn’t worried about, I’m being honest with you ma’am, I wasn’t worried about nothing but him just living. I didn’t care if, if his kidneys or something probably weren’t working, you know. I, I mean, I cared, but I care about his life more, you know.

Many mothers recalled being told it was nothing to worry about now and follow-up examinations would be obtained. However, two mothers were told in the context of “updates” on the baby’s condition during physician rounds. They expressed surprise when learning in this way their baby had IVH.

After they, I guess they got the reading from the, when they, when they knew about it. I didn’t get told two weeks later. And, um, the doctor was going-coming around that night and was just updating us about him. And, um, she mentioned that. And I was like ha? So I didn’t know at first, cause everything was coming back normal. And they was like, “well we did this back in July.” I didn’t get told in like August. So I was like, you know, upset about that.

Mothers were continually confronted with complications their babies were experiencing. Many were occurring simultaneously, so the mother could not process each individually; instead there were a myriad of issues they related to preterm birth complications. Some issues were immediately life threatening, such as respiratory distress or sepsis. Intraventricular hemorrhage was presented as a long-term problem and watchful waiting was employed.

In summary, reframing motherhood in this study is contextually situated within preterm birth complicated by neonatal intraventricular hemorrhage. This is occurring within a biomedical system that uses technology extensively to shift the margins of fetal viability to younger gestational ages and within a sociocultural context in which mothers
believe they are responsible for ensuring a healthy pregnancy and safe delivery for their baby. The following section describes the conditions that influence the processes within reframing motherhood.

**Conditions**

As previously described, conditions are dimensions or concepts that are most relevant to the actions and interactions occurring within the phenomenon. Three central conditional dimensions related to the infant, mother, and course were identified within reframing motherhood (Figure 4-1). Infant constitution is the maternal view of the baby’s health and strength. Maternal attributes are the characteristics of the mothers believed to have the greatest influence on reframing motherhood. Unexpected course is the time following the preterm delivery as mothers negotiate through the NICU stay and first months at home following discharge.

**Infant constitution**

Infants in this study were born at extremely low birth weights and all suffered multiple complications, in addition to IVH, as a result of their preterm birth. Some mothers described the baby as “beautiful, just needing to fill out” while others were frightened regarding the appearance of the baby “with all the wires and tubes”. Although the mothers may have described the infant as appearing frail at birth because they were so small, they believed in an inner strength within the baby. One mother spoke of how scary it was to see her infant during this early phase.

It was scary and it was hard to connect that with what I had felt inside me, you know. It was hard to look at her and know that’s my baby. She didn’t look like a baby. She looked like a little alien doll is what she looked like. She had no fat. Her skin was see-through. It was bright red and see-through. It was really scary.
Although many of the mothers felt frightened by the site of their babies early on, they used descriptors such as superstar, fighter, trooper, strong, and feisty to describe the infants’ will and how the babies handled the situation. By surviving and growing, mothers believed their babies “beat the odds” and were “miracle babies”. The following quote is a mother describing her view of her baby and her feelings about him.

Very strong. I call him my miracle baby. Very strong, and his name is BW, so all the nurses love his name. Oh he’s got a nice strong name and he has really lived up, so far, to his name. I always tell him I’m proud of him cause he’s very strong. From the beginning he’s been a fighter.

Growth of the baby was very important to the mothers. Many spoke of the infant growing so that no one would ever know they were premature. Growth served as a proxy for infant health and was associated with strength. This was an indicator of health that the mothers could experience themselves, as well as being verified through daily weights.

With him, I just looked at like his size. When he, when you see him like steadily growing, I knew enough for him that he’ll be okay. You’re gonna get through this. You’re a fighter. So, that was a thing that I just looked at, just his size is getting bigger. And of course I couldn’t tell if anything inside was getting better but, you know, like I said, he never really, like I said I just looked at his size and was he still growing.

All mothers viewed their infant’s health positively even though there had been complications and setbacks. The term “healthy” was often used to describe the infants, even among the myriad of complications. Intraventricular hemorrhage was one of many complications that mothers described. However, it was different in that it was an invisible diagnosis or complication for most infants because they did not show overt signs of a problem or require intervention. This invisibility was particularly difficult for mothers because they could not readily appreciate what was happening to the baby.
I mean it makes it a little harder cause he looks, like I say, he looks fine like nothing is wrong, or you wouldn’t know that there was bleeding, or anything. But I mean I know that something is wrong internally, but externally he looks great.

Mothers viewed these tiny infants as “babies,” just smaller than expected, who are overcoming many obstacles. They often compared the baby to other babies of the same age, either their own children or what they expected a baby of a similar age to be doing. They looked for confirmation that their baby was developing as expected. There were many references to the baby acting “normal”.

Well, mostly act like a normal little baby. She likes to suck her fingers, likes putting her hand in her mouth. She sucks on pacifiers. She likes to stretch, but mostly a normal little baby.

Physical growth and development was a key indicator to mothers that their infants were progressing appropriately. All mothers believed in the strength of their baby to overcome their perilous start in the world. They viewed these babies as fighters, as miracle babies who overcame many obstacles and could continue to do this into the future.

**Maternal attributes**

All mothers in this study identified three maternal attributes, love, dedication, and faith, as central to reframing motherhood. Each attribute informed and affected the others. Love informed both dedication and faith. Mothers described showing their love through dedication and faith. Mothers also described how much they loved their infants from the beginning, even in the overwhelming environment of the NICU and possibly facing death.

And all I could, I mean, all I remember is just looking at him and just feeling so much love and seeing that he, you know, knowing that he heard, you know, my voice, and knowing that I was there for him, and I didn’t even think about all the wires or anything else. It was just seeing my baby.
Mothers described their love for their baby as independent from the baby’s condition or outcome.

Just if, I mean he’s gonna be loved regardless, but just if, if he’s gonna be like, like a regular child like my other kids, or if he gonna have, um, any learning disabilities, or if he’s gonna, I mean any, have any major complications, as far as disabilities in life.

Many mothers described their love growing over time and some even believed their love was stronger as a result of the prematurity.

It’s stronger. It got more and more stronger, but when she was born as a preemie, it was strong. I had like, yeah, you always, the first time you see your child born, it’s love and it’s strong, but cause she was a preemie, it make it more stronger. And, yeah, I, I love her, I think, more than I did when she was in me a lot more.

Mothers spoke of the love they felt for their infants, but also embodied this love through dedication. Mothers demonstrated this through countless hours spent in the NICU, often times not even being able to touch the infant, but being there meant showing their dedication and love to the infant. Mothers perceived the infants knowing they were there for them. One mother stated, “as soon as he heard my voice, he reacted to it.” However, for many mothers, it was also important to show staff their dedication and love for the infant. One mother in particular believed this helped her advocate for her baby.

We can’t remember ever having a nurse who pushed our concerns aside…But, because we were parents that were here around the clock or our parents were here with him, they know that we really knew him. They knew that we were really absorbing the information and understanding what was going on, and so I think that played a big part to it as well.

Mothers believed that their dedication to the infant could positively influence the outcome of the baby, but their dedication was also independent of the outcome of the
baby. As stated by one mother, “I’m the type to keep everything on my end just to be sure that he gets the best care and the best outcome for him in the future.”

Lastly, faith was evident in all mothers. Faith manifested in mothers in several ways: faith in a higher power, faith in the baby, faith in themselves, and faith in biomedicine. Many mothers explicitly spoke of faith in God that allowed them to handle the situation regardless of the outcome. This faith was also believed to get the baby through difficulties. One mother stated, “I mean, I have faith in God that he’s going to see D through everything.” Another mother believed from birth that her baby would be okay because of her faith in God.

I mean, I never doubted God and I never doubted what he could do for G, and I already knew that, you know, G would be okay, so it just took me to keep having the strong faith, keep praying over, and you know, just praying in general.

Many mothers spoke of the faith they had in the baby. The baby had demonstrated an ability to overcome complications just by surviving; therefore, mothers had faith that the baby could continue to overcome obstacles in the future. One mother described how her faith in her baby could influence his outcome. “I think that the more hope and faith that you can have in your child, I think the better the outcome would be.” Mothers also described faith in themselves to positively influence the future of the babies through ensuring that all their needs were met.

Whatever she needs, we’ll give to her to make sure that she’s taken care of and the problem is being taken care and she’s getting the treatment she needs.

But I also know that he’s still developing and as long as I work with him and, of course, have faith that he’ll reach those milestones, probably sooner than later.
Often times this was described as a partnership between the mothers and biomedicine. The mothers’ role was to ensure proper follow-up with doctors and therapists who would use their skills to help the baby thrive. Biomedicine had allowed the babies to survive and would also help them overcome any complications encountered along the way.

They tell me things like shunts and reservoirs and stuff like that. And this just might be me just being naive, but I’m feeling like if they put these things in, he’s going to be fine. He’s going to be running, jumping, doing cartwheels around the house.

Medical follow-up and ongoing therapy was seen as particularly important to helping the babies overcome their preterm birth and subsequent complications. Most mothers believed their baby would need some form of therapy and this would help them achieve their developmental milestones. These types of faith were not exclusive of one another as this mother stated.

You know, we could have wonderful doctors and God have meant, touched their hands and did a wonderful job. You know, we just don’t know, I guess because it’s so early, but I think with a wonderful, with a mother by his side, his dad by his side, support system, I think he’s going to go far, regardless of what outcome it is.

This mother acknowledges an uncertain outcome, as did many of mothers as they proceeded through an unexpected course into motherhood.

**Unexpected course**

Once the baby was born, the unexpected course these mothers found themselves upon was completely foreign and an unexpected entry into motherhood. None of the mothers in the study had previous experience, either through themselves, a family member, or close friend, with extreme preterm birth. They were not prepared for their babies to be born at such young gestational ages and did not know what to expect. The following is one mother’s description of the experience.
His due date was August 3rd, but he came April 25th. 25 weeks. So the whole thing just surprised me. I’m with Healthy Start. So there’s a nurse who comes. She was coming every week, and we would talk about the pregnancy and everything, but we never talked about if the baby were to come early and what to do and just, I had no clue what to do at the time.

Mothers realized very quickly that reality was very different from the experience they had planned. As stated by a mother, “I really didn’t know what to expect until, you know, everything started happening.” Many thought their baby may die; therefore, early in the course, the maternal focus was on survival of the baby. Doing everything to save the baby was paramount. Although for most there were no explicit decisions made about resuscitation prior to birth, the mothers wanted resources employed to save their baby.

They knew that he was coming, they just was like, okay, we’re going to try to make him live. I looked at them, like, yeah, I want everything. I want my son, you know.

Once resuscitation had occurred, the concepts extreme uncertainty, riding the roller coaster, and swirling emotions dominated the NICU course and reframing motherhood.

**Extreme uncertainty.** After delivery, these infants faced many obstacles as they fought to survive. Many of the mothers were provided statistics regarding chances of survival and chances of complications in the time just after delivery.

He said that there was a less than 30 percent chance that she was gonna survive her first 24 hours and less than 10 percent that she would continue to grow and become healthy and normal. He said that less than 10 percent of babies born at that gestational age go on to live full normal lives.

Other mothers received information that was much more vague, such as possible learning disabilities, cerebral palsy, and blindness. However, no one could say with certainty the complications the infant would face or how the infant would fare. This created a sense extreme uncertainty. This was a filter through which subsequent
information and occurrences were viewed. Intraventricular hemorrhage added to this uncertainty because now the infants were at greater risk for neurologic damage. A mother describes a conversation with a neonatologist who is discussing IVH severity and possible outcomes.

I mean she didn’t give me false hope by any means, but she also told me that, you know, here in the NICU they see babies with, you know, threes and fours [IVH grade] that beat the odds statistically, and with therapy, and with everything else, and that sometimes you have a one-two [IVH grade] that can end up being devastating and you a three-four [IVH grade], and the child does fine, and I know, I understand statistically.

This uncertainty allowed mothers to have hope and focus on the possibility of a positive outcome because no one was able to predict with certainty a negative outcome. Although the uncertainty created a sense of fear related to the unknown future the infant may face, it also created a sense of hope that it was possible that the infant would be okay.

I have gone online and looked up parents’ stories of children with IVH who have succeeded and who are having a good quality of life now, and that has given me additional hope for him and whether other moms want to do that and again maybe you would think that that’s giving false hope. You have to go into it knowing that there are children who beat the odds.

Uncertainty permeated the NICU course that mothers described as riding the roller coaster.

**Riding the roller coaster.** The course in the NICU was never predictable for these mothers. It was fraught with accomplishments followed by setbacks for the infants. This instability was difficult for the mothers.

She came off the jet vent [ventilator] and went on a conventional vent and we were so excited. You know, that’s progress, that’s great, it’s a step down. And then we come in the next night and the jet vent is back and I’m like, what?
They never knew what could happen next to their baby and always feared a dreaded call from the NICU. As one mother stated, “It’s always really terrifying when you see the, the doctor’s phone number coming up on your phone.” This mother used the term *roller coaster* to describe the ups and downs encountered as the infants attempted to overcome their preterm births.

Yeah, it was a roller coaster. I mean, like I tell anybody, there were some good days in the NICU; there were some bad days in the NICU, and you never knew what to expect. A good day can turn into a bad day, and a good day can just stay a good day.

Early in the course, all the infants experienced IVH at varying grades. However, there were many other life-threatening complications the infants faced during this early time, including respiratory distress, necrotizing enterocolitis, and sepsis. Many of these occurred simultaneously and required immediate life-saving measures, such as changes in ventilators, antibiotics, and surgery. Intraventricular hemorrhage remained present, but did not require any intervention in most cases. Infants underwent weekly head ultrasounds for monitoring, but no treatment was initiated with the exception of two infants who required ventricular punctures for removal of cerebrospinal fluid and eventual ventriculoperitoneal shunt placement. This complication remained invisible for most mothers who were told about it, but did not see signs of its existence. Meanwhile there were many other issues faced by the infants that also contributed to the roller coaster, including feeding difficulties, retinopathy of prematurity, apnea, and bradycardia that also required intervention. One mother stated, “Just, just about everything that could go wrong, at some point did.” Another mother described an episode she witnessed in which her infant had to be resuscitated.

One morning I came in to see him and he, I guess he had just got finished eating and then all of a sudden he just threw up and the he brady’d. I guess
he was choking at the same time and the nurses came over there and then they was like come on G, come on G, and then G couldn’t catch his breath back and he turned blue then his numbers just went down. And they coded blue and then everybody just bust in from everywhere and then they did a couple of chest compressions on him and then he was okay. Then he was just looking around with his pacifier like nothing had just happened. And it was just life very scary.

Moments like these created intense emotional responses for the mothers. This same mother went on to describe how she felt after this experience.

I was on edge for about a week or two. I was having nightmares and just really couldn’t sleep, just worrying about was he okay…The next day when I drove in the parking lost my heart just started beating really, really fast. The closer I got to the NICU, the worse I felt.

Mothers were on an unplanned and undesired roller coaster. Constant uncertainty and the intensity of sudden changes created strong emotional responses within the mothers.

**Swirling emotions.** Experiences in the NICU created a whirlwind of intense emotional responses in the mothers (Figure 4-3). Emotional swirling represents the dichotomy of emotions that mothers go through following preterm birth complicated by neonatal IVH. Not all mothers experienced every emotion identified; however, they all experienced emotional swirling in which many emotions were occurring simultaneously. Many of these emotions, such as love, blame, feeling of being robbed, and uncertainty, have been previously described as part of this experience. Yet while mothers were having these emotions, they may have also been experiencing anger, thankfulness, devastation, powerlessness, happiness, and/or disbelief. Many mothers described feeling as though they needed to stay strong for the baby. So even though they were experiencing these intense swirling emotions, while in the NICU, they needed to stay strong so that the baby would not sense any negative emotions. This mother described
not wanting to cry around the baby because of the possibility of negatively influencing the baby.

I wanted to be there, but I didn’t want to cry while I was there with him. Cause I kind of, yeah, he is a baby, but I don’t wanna like, I feel like if I get depressed, maybe he’ll know that I am sad and I don't wanna let him be sad and then start crying, and then I just feel like the energy between me and him, if I’m happy, maybe he’ll be happy.

Other mothers also described the need to stay strong or remain positive for the sake of the baby.

I guess, is the main thing that I really want him to know that I'm positive with everything. And hopefully he'll be positive with everything and keep growing. And keep on being strong and everything.

As mothers were experiencing swirling emotions they felt compelled to remain strong, positive, and hopeful for their infant even though they were experiencing such turmoil. Mothers felt that it was very important to keep their emotions from erupting while close to the baby. When mothers allowed these emotions to be exposed in the NICU, they felt guilty and quickly tried to regain control. Mothers sensed a connection to their infants and believed that negativity on their part could possibly influence the infant negatively. Another mother stated, “stay positive and to keep it together for your child.” Putting the infants perceived needs before the mother was evident throughout this experience.

In summary, infant constitution, maternal attributes, and unexpected course were core concepts identified as most influential to the central process of learning to mother a preterm baby with IVH within the explanatory model reframing motherhood. The following section discusses the ways in which mothers learn about their baby and incorporate this understanding into their lives.
Processes and Strategies

Learning to mother is the dynamic process in which mothers are learning about their babies and what these unexpected circumstances mean for their lives. These mothers have experienced motherhood in an unanticipated way. When they learned of their pregnancies, they had an expectation of the experience and this expectation was completely interrupted. Their babies are also very different than anticipated. Now the mothers are attempting to understand and make meaning of this new motherhood and integrate it into their lives. As previously described, there is a high level of uncertainty for both what this means for themselves and their babies.

Learning to be a mother of a preterm baby with IVH involves a time of intense information gathering (Figure 4-1). Sometimes the information was sought by the mother and other times she received and processed information, although this information was not always desired.

I got to the point where I don’t want to hear the facts anymore. Just, I told the doctor, I don’t want to see you. I don’t. I’m running from you guys. I don’t, I don’t want to hear the facts anymore. So going forward, you’ve told me one time. I don’t want to keep hearing it. Thank you.

Information came from multiple sources and often resulted in mothers feeling completely overwhelmed. Mother one stated “I regret not asking that many questions, but, you know, it was just, it was very overwhelming.” The primary sources of information included healthcare providers, typically doctors and nurses, as well as friends and family, internet sources, and their babies. The information came in the form of verbal messages, written messages, actions, and cues. Some mothers actively attempted to limit their information intake primarily by avoiding conversations with
doctors, as previously described, or avoiding certain types of information while researching topics on the internet.

I tried to go on the March of Dimes and see some of the babies, some of the success stories. But I have to watch for what I look for [nervous laughter] because they can terrify you.

Provider information was received by mothers through verbal messages or actions. Verbal messages were provided in the context of arranged meetings or bedside consultations while provider rounds were being made or care was being delivered. Mothers received updates on the baby’s condition, as well as information related to outcomes. After the initial diagnosis of IVH was made, most information provided were updates regarding IVH severity and possible implications of the bleed.

And you know, he just said he thought for a while actually that bleeding on the brain was the reason that she wasn’t eating. Was that there was something being hindered there, by the amount of bleeding in the brain and they were doing ultrasounds her head frequently and X-rays and things to determine the extent of it.

Intraventricular hemorrhage was often discussed in terms of resolution. Mothers awaited or avoided updates regarding “resolution” of the blood. Many mothers spoke of the blood dissolving. The nurses related information to mothers in terms of their past experiences with babies who also developed IVH. Nurses often comforted mothers by relating positive stories. Physicians also provided positive stories, as well as statistics and the possibility of long-term complications related to IVH. Uncertainty dominated the information related about IVH. “It could get worse or it could get better.” Another mother spoke of the uncertainty in predicting future outcomes.

So, you know, they told me, with what she, the amount that she has as of the last ultrasound, they can’t really predict what effect that’s going to have on cognition and things. You know, in, in the future. How it’s going to affect her learning and her growth and development. They, they don’t really know, you know, what effect it’s gonna have.
These updates regarding the status of IVH often occurred after a head ultrasound was performed as a routine follow-up. Most mothers who were shown head ultrasound images believed that it helped them better understand IVH. “They started showing me pictures of his brain and I started seeing how kind of severe it was and I could start understanding, because somebody actually showed it to me.” More often, daily communication from providers was about adjustments in care related to improvements or complications in the infant’s status. Respiratory support, feeding, and growth were common themes in communication about the care of the baby. Nursing communication was often related to teaching the mothers about taking care of the infants, such as feeding and bathing.

Mothers also gathered information from providers through their actions regarding the infants’ treatment. Surgeries, special diets, and study enrollments were provider actions that mothers used as indications about the infants’ progress.

I do think it is a good sign that the surgeons stepped in so aggressively because when they do decide to operate and decide to step in they do know that whole picture of the baby. So probably if they thought it was if it was cruel at this point, that they wouldn’t have, uh, necessarily acted so aggressively on it.

Often times, these were viewed as positive signs that treatment was continuing and progressing. Mothers also observed the intensity of care provided by staff as cues to the infant’s health and current status. This mother stated “people are not all around him and they’re not having to call a code on him, and he seemed to be stabilizing.”

Information was also gathered through conversations with family members, friends, and other mothers in the NICU. Information from family members tended to provide support and reassurance the mothers. Fathers and grandmothers in particular would reinforce the strength and will of the baby to mothers. “They said he was feisty.”
Grandmothers often looked for positive stories of preterm babies on the internet or through acquaintances and related these back to the mothers. One mother spoke of a friend of her mother who experienced preterm birth.

Um, my mom’s friend was a premature baby and he was, he was, uh, triplets, and they all died but him. And they were thinking that he was going to die, and his, like, he’s like, a teacher in college.

Friends also provided similar information regarding success stories. Mothers in the NICU often compared stories of their experiences and those further along the course provided support. Mother 11 stated, “Also, other mothers in the NICU, as well, so that helped, as well, and that just give me some kind of hope and faith”. Information dissemination in this context was provided as a source support to the mother.

Mothers also sought information from internet sources. The information source was different in that the mothers controlled the information they received. One mother stated, “I’ve, uh, definitely stayed away from researching the whole issue of IVH and statistics.” They used the internet for two purposes. The first was to gather information regarding outcomes for preterm infants. Many mothers spoke of being careful to only read about positive stories for inspiration. This provided hope that after riding the roller coaster in the NICU, it was possible to have a good outcome.

I’ll read on the internet or hear from the other parents about their talk about their experience. Oh, had, my child had the same thing and look at him now. That helped, as well. So it’s just giving me hope that, it made me feel better.

The second purpose was to increase understanding of the information provided by physicians. This was usually related to a specific diagnosis or complication. Mothers often felt as if they did not fully understand the information provided by physicians. “If I felt like I didn’t understand something and I wanted more details on that, I would just
look it up on the internet.” Some mothers described not understanding because of heavy accents or technical terms used to relate the information.

The most significant source of information gathering according to mothers were infant cues. Mothers assessed behaviors and appearance of the infant to determine how well the infant was doing.

More than anything, just watching him and seeing how he is doing. I was here with him all day, he was maybe asleep for 30 minutes out of the whole entire day, and he was just looking around. I had a bumper for him. He looks at his bumper, he looks at his mobile, he’ll follow things with his eyes, and so I think that, and he self soothes himself, which I know is very important.

The common theme was the normality of the both infant appearance and behavior with the caveat that the baby was just smaller.

If he didn’t like, if he just laid there. Pretty much he holds his head up, turns his head, lifts his head, kicks, use his arms, look at you, and you know, pretty much like a normal baby would do so.

Eleven of the twelve mothers described their infant as acting like a “normal baby.”

Information gathering as previously described was occurring, being interpreted, and incorporated simultaneously into the lives of the mothers in ways that made sense for them. Often there were competing messages contained within the information, especially information from differing sources. Mothers had to interpret the information and make sense of it to build their own explanatory model in an effort to understand what is occurring and what it meant for them. For example, a mother was told by the neonatologist that her baby had IVH and had a very low chance of surviving without major long-term complications, such as cerebral palsy and blindness. He may never walk, talk, or interact with her. However, it was also said that IVH is nothing to worry about now. At this same time, he was being taken to surgery to treat an intestinal
infection and enrolled in a study determining the effects of specialized infant formula. The grandmother was relaying how strong and feisty she believed the baby to be to the mother. The mother was seeing a baby that was tiny, but otherwise appeared to look like a “normal” baby. There were no outward signs of bleeding in the brain. He was showing improvement in his respiratory status. The nurse relayed stories of children with IVH who have little or no disability. The mother then went home and read stories of “miracle babies” on the internet. Then new information was provided on the infant’s status. This ongoing cycle of information gathering, interpreting, and making sense is how the mother was developing her understanding of the situation. It is constant and continuous with little escape.

Through this process, mothers begin to develop strategies to help them deal with the situation. They redefine their hopes, reconstruct expectations, and live in the moment. Hopes and expectations are closely aligned. They hope their infant will continue to be the “miracle baby” and the progress made will continue. The baby will continue to overcome obstacles. They begin to expect there will be delays and the infant will not have the same pace of developmental milestones as a full-term baby.

Obviously before this happened, my expectation would’ve been to not even have to think about cerebral palsy. Now my expectation would be, you know what, even if he, you know, if we work with him enough, if he just has a mild form cerebral palsy, that’s a win, maybe just something in the arm or the leg, that if we do enough therapy for him. I think that we’re realistic in knowing that we’re gonna have to do all the therapies, but hopefully we can get him to a point where he’s able to be self-sufficient.

They hope the baby will achieve milestones. They expect it to be a long road and likely requiring ongoing therapy for this to occur. They hope the baby is happy and their life is not too hard, but they expect there to be challenges. They hope the baby is “normal.”
Yeah, I mean, ideally you want your child to be able to go to school and get married and do all of those things. Um, I mean quality of life. The quality of life to me and what we hope and pray that he’s going to be able to walk, be able to learn, be able to talk, be able to feed himself, all of those. All of those things, and then just hope for the, just hope for the best, just keep working with him, and so he can reach his full potential.

The mothers strive to live in the moment and not to look too far into the future. It is too overwhelming and uncertain. Today they will deal with today’s issues; if there are new issues tomorrow, they will deal with them tomorrow. “I want to focus on right now, you know, what’s going on now, and me getting through this phase with him, and then we go to the next phase.” Another mother stated, “You can’t look long-term because if you do, you’ll just, it’s just too overwhelming”. Even though much of the information they receive, especially regarding IVH, is projected toward the future.

In summary, there is a constant flow of information being received, interpreted, and incorporated, resulting in the development of strategies by mothers. Mothers redefine hope, reconstruction expectations, and live in the moment to help them deal with the situation. This hope, expectation, and determination in turn affect information gathering, interpreting, and making sense. The resulting consequence is development of a maternal explanatory model in which hope and uncertainty prevail. Mothers adjust their expectations to fit the situation and live in the present. The result is a reframing of motherhood.

**Consequences**

Two major consequences were identified within reframing motherhood (Figure 4-1). Mothers acknowledge a new uncertain life trajectory for themselves and their infants. It is unclear what the future will hold related to long-term effects of a preterm birth complicated by IVH, as well as other difficulties. Mothers have learned a great
deal thus far into their journey, but this does not make the unknowable knowable. How will the baby fare? Authoritative knowledge attained by mothers related to outcomes may be set aside and other ways of knowing relied upon in order to maintain hope. This hope was instrumental in helping mothers cope with their roller coaster ride. Hope allowed mothers to come into the NICU and face setbacks. Hope allowed mothers to face the everyday uncertainty and continue on with therapy sessions in an effort to help their child have the best possible outcome. No one knows what this outcome will be, so they will continue to hope for the best possible outcome within their new life trajectory.

Mothers found purpose in a situation in which they had previously described themselves as useless. They could mitigate the effects of preterm birth and its subsequent complications through their commitment to their infant. Maternal commitment to remain dedicated to their child and partner with biomedicine gave their child the best possible chance at a “normal” life. Through therapy, mothers could learn how to work with their child to help them achieve developmental milestones. Although there may be developmental delays, achieving milestones and independence was possible, but not guaranteed. Mothers found a powerful way to influence the future.

**Discussion**

Reframing motherhood is a complex phenomenon that occurs within the context of preterm birth complicated by IVH. Preterm birth is an unanticipated event that disrupts maternal expectations for herself and her baby. A shift occurs in her views of what it will mean to be a mother. Now she is a mother of a preterm baby with complications that will likely create long-term effects. This process occurs under specific conditions of the infant, mother, and course as previously described. Intense information gathering and processing occurs among swirling maternal emotions. Sometimes the information
gathered is conflicting. Mothers use multiple ways of knowing to determine the most relevant information. They may even discard information that conflicts with their ability to maintain hope. Hope allows mothers to keep moving forward within an overwhelming, uncertain situation. They adjust their hopes and expectations to fit the current context. Living in the moment allows them to deal with the most immediate issues and not lose hope. Mothers gained power in the situation by believing in their own ability to affect the long-term outcome of their babies.

Summary

This chapter provided the individual stories of each mother’s experience with preterm birth in order to provide the context in which reframing motherhood occurred. Reframing motherhood was established as the central perspective in which mothers created understanding and meaning regarding their infant’s preterm birth and subsequent complications with a focus on neonatal IVH. Intraventricular hemorrhage was one aspect of an extremely complex phenomenon that cannot be understood in isolation of its context. In the following chapter, the research questions will be explicitly addressed and implications of the study findings will be discussed.
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NR-No Response  
HS-High School  
SC-Some College  
AD-Associates Degree  
BD-Bachelors Degree  
GS-Graduate School  
M-Mild (Grade I-II) S-Severe (Grade III-IV)  
* Customer Care Representative  
**Customer Service
Figure 4-1. Reframing Motherhood.
Figure 4-2. Complications of preterm birth
Figure 4-3. Swirling emotions
CHAPTER 5
DISCUSSION

Preterm birth with its subsequent complications is a very complex phenomenon. Intraventricular hemorrhage is one aspect of this event that is considered by healthcare providers as an important determinant of neurodevelopmental outcome after preterm birth (Boyce, Smith, & Cato, 1999; Behrman & Butler; Baron, Ahronovich, Erickson, Larson, & Litman, 2009). However, little is known about how this diagnosis is perceived by mothers. The intent of this study was to explore the process of becoming a mother to a baby with IVH for the purpose of understanding the meaning mothers attribute to IVH and how it is developed. Three research questions guided the study:

- What are maternal beliefs related to the cause, course, cure, and consequences of neonatal IVH?
- How are beliefs about IVH constructed within the preterm birth experience?
- How does preterm birth and neonatal IVH affect motherhood?

This chapter discusses the study findings, compares study findings to current literature, addresses limitations, and offers implications for practice and future research.

Summary of Research Findings

Mothers in this study regarded preterm birth as an unexpected and overwhelming life event that was very different from what they had anticipated. This finding is well documented within neonatal literature (Calam et al., 1999; Golish & Powell, 1993; Hall, 2005; Jackson et al., 2003; Layne; 1996; Lee et al., 2009; Lupton & Fenwick, 2001; Ricciardelli, 2010). The disparity between anticipated and actual events resulted in an intense time of meaning development (Lee et al). During this time, the mothers began to reframe motherhood to fit their new life circumstances (Figure 4-1). Their motherhood was filled with uncertainty and they had little control. It was important for
mothers to learn about being a mother of a preterm baby with major complications so they could begin to develop meaning and understanding of their current circumstance. Intraventricular hemorrhage was viewed by mothers as one complication among many (Figure 4-2). As mothers gathered information, interpreted information, and incorporated information, they developed strategies to help them deal with the situation. Living day by day, reconstructing expectations, and redefining hope helped mothers to persevere within their new life trajectory and learn to a mother to this baby. The following sections will address maternal understanding of IVH, how beliefs are constructed, and effects on motherhood.

**Intraventricular Hemorrhage**

Intraventricular hemorrhage was viewed as one complication among a multitude during the NICU course. There was not a hierarchical structure of importance placed on the individual complication. The focus tended to be on the immediate problem upon which medical care was focused. For example, if there were respiratory issues that required a change in treatment, then this would take precedence. If there was an infection that required antibiotic therapy, then this would be the immediate maternal concern. As previously described, intraventricular hemorrhage remained “invisible” therefore, rarely took precedence. Invisibility of the diagnosis occurred because there were no overt signs or symptoms associated with IVH that mothers could appreciate. The infant did not display cues of neurological damage; whereas with other complications, such as respiratory distress, there were signs the mother was able to see and interpret. This resulted in information the mother received about IVH from providers seeming to be incongruent with infant cues. Another contributing factor was the lack of immediate treatment for IVH. Treatment was only instituted if there were further
sequelae such as hydrocephalus. When treatment was required, it was weeks to months after the initial diagnosis had actually been established. Due to these factors, IVH was not viewed as an immediate concern, but something that may need to be dealt with in the future if there are further sequelae.

**Cause**

All mothers in the study stated they did not know the cause of IVH. They recalled being told that this was a common occurrence in preterm births, but not specifically the cause. Most surmised IVH was related to prematurity, specifically the brain being underdeveloped. This was a source of guilt for mothers. They blamed themselves for the preterm birth therefore, the IVH. A few mothers went further to say that the delivery contributed to the development of IVH because the baby was so small that there was trauma to the baby’s head. One mother even believed that it could have been caused by the healthcare providers. Another mother stated that it may have been caused by the medications that the baby was being given. When asked, mothers stated that it was important for them to know the cause. This finding is consistent with previous research that found parents want as much information as possible about the condition of the baby (Alderson et al., 2006; Brazy et al., 2001; Kowalski et al., 2005; Mok & Leung, 2006). Mothers created explanations about the cause of IVH that made sense to them, but could lead to misunderstandings and distrust. This finding is important because providers can help mothers form an explanatory model about IVH that includes an explanation about the cause that may diminish guilt and blame. Previous studies have shown that information can help mothers feel more control over the situation (Alderson et al.; Kowalski et al.; Mok & Leung).
Course

The course of IVH was fraught with uncertainty. Early in the course, mothers recalled being told that IVH was nothing to worry about now and that it would be tracked with head ultrasounds knowing that it had the possibility of “getting better or worse”. There was a wait and see approach employed by healthcare providers, so mothers did not focus on the diagnosis. Most mothers also recalled being told about the grading system for IVH. Grades I-II were believed to be mild and “nothing to worry about.” It was believed to only be a problem if it got worse. This is an important finding because research regarding outcomes of preterm babies, even with grade I-II IVH, remains inconsistent (Savage & Kavanaugh, 2004; Behrman & Butler, 2007). Grades III-IV were described by the mothers as more severe, but the focus was on the belief that the blood would “resolve or dissolve”. This represented an end to the immediate problem of bleeding, but not possible future consequences. As long as blood was present, mothers remained concerned about the possibility of it getting worse. This is another important finding because IVH occurs within the first few days of birth, so continued or rebleeding later in the course is not likely.

No medical interventions for IVH were recommended for most babies in this study; therefore, it remained largely “invisible” to these mothers. Although mothers were told their baby had IVH, there was no evidence provided in the form of symptoms or treatments. Some mothers were offered the opportunity to view the head ultrasound that demonstrated the bleeding. Although they did not necessarily understand what they were seeing, it provided evidence of the problem and most believed that it helped them to better understand IVH. Updates were provided to mothers following subsequent head ultrasounds related to resolution of the blood. Mothers looked forward
to receiving news that the blood had “dissolved” which meant they could eliminate one problem. They felt that once this happened, they no longer had to worry about IVH. However, they continued to acknowledge that there was a possibility that the baby would have future problems or delays related to prematurity, but there was no way to predict the problems. They would have to watch and see how the baby developed.

Cure

When asked, the mothers stated there was no cure for IVH. Most stated that they did not know about any specific treatments for IVH. The blood had to “dissolve” on its own which would be the cure; however, some mothers spoke of possible complications such as hydrocephalus which may require a shunt for treatment. The two mothers whose infants required a ventriculoperitoneal shunt described the shunt as treating this complication. Once this was done, the baby would have a better chance of not having developmental problems. Both of these mothers believed that with treatment future consequences would be mitigated.

Consequence

The consequence of IVH was the biggest unknown. All mothers acknowledged that IVH may contribute, along with prematurity, to future problems with development and learning. Mothers listed potential complications such as cerebral palsy, blindness, deafness, learning disabilities, and developmental delays. None believed their infants were showing signs of these problems, with the exception of expected developmental delays. Delays were expected because of the prematurity. However, they believed the delays could be overcome through their dedication and commitment as a mother. All mothers stated they were committed to working with their infants and seeking all possible resources. The medical system, especially rehabilitation, was seen as
important in helping the infants. The mother would utilize these services to help the baby progress, as well as teach herself how to best take care of the baby to positively influence development.

Maternal beliefs related to cause, course, cure, and consequence are very important to understand. Based on the principles of SI and explanatory frameworks, people act towards things based upon meaning; therefore, maternal actions will be driven by their beliefs in these areas. None of the mothers were able to verbalize the cause of IVH, so they created an explanation that made sense to them sometimes attributing blame to themselves or the healthcare provider. Mothers stated it was important for them to understand the cause of IVH because they believed it would help improve their overall understanding, which was very important to them. All mothers worried about the possibility of the IVH worsening as part of the course; although, it was unlikely because the infants were past the likely period of continued bleeding. The cure was noted to be the absorption of the blood unless a complication, such as hydrocephalus, arose which would require further treatment. The consequence was the most uncertain. Mothers whose babies had mild IVH believed that there would not be long term consequences of IVH and related possible developmental issues to prematurity. Mothers whose babies had severe IVH believed that there could be long-term consequences, but the possibility would be lessened once the blood resolved. Each of these areas serve as a possible place in which to intervene as the mothers are developing their beliefs about IVH. This study contributes significant knowledge about preterm birth and specifically IVH. There are no other studies in the literature that
describe maternal understanding of IVH. Specific diagnoses have rarely been studied within the NICU experience.

**Belief Construction**

Beliefs about IVH were constructed through the process of learning to mother. This was an intense time of information gathering, interpretation, and incorporation. Information came from many sources. Mothers recalled being given information about IVH from healthcare providers that was generally related to outcomes or consequences of the diagnosis. This information was always framed within the context of uncertainty. The baby could develop cerebral palsy, have learning disabilities, or be blind; however, no one could predict which infant would develop which outcome as a result of IVH. Mothers told stories of children who had experienced severe IVH and developed few complications as a result. Such stories were provided by physicians, nurses, friends, and family. Mothers recalled physicians typically providing more information related to complications; whereas, nurses were recalled more frequently as providing information in terms of possible developmental achievements. Therapists also provided information about the baby’s developmental progression. Mothers generally viewed this information as positive because the focus was on infant achievement.

Provider actions and infant cues were also sources of information. Mothers believed that medical care would not be continued in futility so as treatments continued and even expanded, mothers’ beliefs in the possibility of a positive outcome, meaning close to normal development, increased. The baby was also a source of information as the mother interpreted cues from baby. Mothers believed that the babies were acting “normally” or as expected. This was viewed as positive and reassurance that thus far
the baby’s development was normal. They did not believe this meant the baby would never have problems in the future, but it was a positive sign.

The internet was another information source that was frequently utilized. It was used as a way to gather information while controlling the content of information. Mothers used the internet primarily for two reasons. The first was a way to obtain more information and greater understanding of what the physician said. Barriers to communication included medical vocabulary not well understood by the mothers, thick physician accents, and being overwhelmed. Mothers stated they felt more comfortable gathering information on the internet and then returning with their questions. This gave them time to process the information more fully. They also used the internet to find miracle stories of babies who had succeeded under similar circumstances. Mothers stated they were careful to only read what they considered “positive” stories. They acknowledged that they may consider a story a success that other mothers may not. They were not looking for stories of perfect outcomes; but rather for stories of happiness. These stories were used to inform the strategies that mothers were developing to help them deal with their situation.

Mothers were required to interpret and incorporate massive amounts and types of information. Often this information was conflicting and overwhelming, so mothers chose which information to incorporate into their explanatory models. Mothers used information to develop strategies to help them reframe motherhood in such a way that they could continue to face their uncertain future. Three strategies were identified: redefining hope, reconstructing expectations, and living in the moment.
Redefining hope

Maintaining hope was a strategy central to this process, but hope needed to be modified during the NICU experience in order to reframe their motherhood within the current context. Mothers needed hope to help them persevere through the difficulties associated with preterm birth, as well as future consequences. Because the situation was fraught with uncertainty, mothers could choose to remain hopeful and focus on the positive outcomes. Mothers were hopeful that their babies would be happy and progress in development. Their ultimate hope was for a developmental trajectory where all milestones were achieved, although later than full-term babies. However, they acknowledged that this may not happen; it was the goal. They needed to maintain hope in order for this to be possible. They would need to remain dedicated to the babies in order to help this progression along and it was essential to maintain hope.

Reconstructing expectations

Another strategy used by mothers to reframe motherhood was reconstructing their expectations. They developed new expectations congruent with their experience. This was particularly evident in expectations about development. They no longer expected the baby would learn to walk on his/her own. Now there would be hours of therapy and working with the baby in order to learn to walk. They expected to use biomedicine extensively in an effort to help the baby progress. They had given up their expectation to take the baby home from the hospital upon the mothers’ discharge. They now expected their babies to spend their first several months of life in the hospital and expected to take them home sometime around their due date. They were developing the expectation that they would care for this baby in a different way than a full-term
baby, including meeting more physical needs. Due to the many unknowns, mothers felt it was very important not to focus on the future.

**Living in the moment**

Mothers felt it was very important to live in the moment. This strategy helped mothers focus on current issues the babies were facing. The future was overwhelming and there were immediate problems that needed to be handled. The future was viewed as uncertain and unknowable, so there was no reason to focus on it. They did not dismiss the possibility of problems arising in the future, but they needed to get through day-by-day.

Using these strategies, mothers reframed motherhood in a way that maximized their ability to deal with the situation. It was important for these mothers to gain control over this situation in which they felt powerless and overwhelmed. Development of these strategies allowed mothers to begin to regain some control in their lives. They had accepted that their motherhood would be different than they had once anticipated.

**Motherhood**

Preterm birth and subsequent complications, including IVH, had many effects on motherhood. From the beginning, their motherhood was full of uncertainty and powerlessness. However, all mothers expressed a deep love for their babies. Their love was not contingent upon outcome. Using the strategies described, mothers reframed their motherhood to maximize their power within the situation. Mothers needed to remain strong in the face of adversity because this would help their babies to remain strong. Mothers believed their attitude and beliefs about the situation influenced how the baby would react. They acknowledged a new uncertain life trajectory in which there will be many unknowns. However, they retained the power to influence the
situation by remaining dedicated to the baby. They could help mitigate the consequences of preterm birth by remaining strongly committed to the baby. Hope was extensively relied upon to help them face the ongoing stressors. They believed that they must maintain hope in order to stay committed in the face of such uncertainty. The following section will discuss the research findings within the context of the current literature.

**Discussion of Major Findings and Second Literature Review**

During the course of this study, I began to realize the major differences in understanding between mothers and providers or the differences in their explanatory models. These differences were not based on misunderstandings of scientific information or evidence. Through these stories, I realized that mothers did not view their babies in terms of a myriad of complications related to preterm birth or the possibility of a negative outcome. They viewed their babies as strong, albeit tiny beings, full of possibility and hope. Mothers attempted to make meaning of this new situation. This required that they reframe motherhood to be congruent with the current context. These babies were born preterm and would have many obstacles to overcome, but it was possible for them to have a fulfilling life of happiness. These mothers entered motherhood in an unexpected way; however, they choose to incorporate this experience into their life in a way that relied on hope for a good life for their babies. They adopted distinct strategies to help them accomplish this.

The provider perspective, as interpreted by the mothers, seemed to be focused on treatments and outcomes. As mothers recalled their conversations with providers, they tended to focus on two areas. The first were updates in medical care of the baby. The types of treatments being utilized and expectations were frequently discussed.
Secondly, outcomes related to the baby were discussed. These tended to be future oriented focusing on long-term issues. This was in direct conflict with the maternal strategy to live in the moment. Although providers were not interviewed in this study, this finding is consistent with Payot and associates (2007) concept of differing agendas of parents and providers during the surrounding preterm birth. Parents are focused upon the baby and transitioning into parenthood and providers are focused on providing information related to morbidity, mortality, and prognosis. Mothers are likely experiencing guilt and feeling overwhelmed during this transition and may need support, as well as time to adjust prior to being able to digest volumes of information. The subsequent sections address the major findings within the current literature.

**Context**

Mothers in this study believed in the power of biomedicine to save the lives of their infants. They wanted all possible resources utilized. Ricciardelli (2010) describes a desperate love for the infant that drives a “fight for life” and the decision was not about options or the future (p. 2). When mothers in the current study were asked about decision making, they described being told that everything would be done to try to save their baby. This is what they overwhelmingly wanted; however, they were never asked to make a decision about life sustaining measures or treatments.

Another belief in biomedicine was the protective nature of prenatal care. The mothers overwhelmingly believed that they had participated in prenatal care which should have afforded them protection against a negative pregnancy outcome. This phenomenon is a widely shared belief about the power of preventative care in pregnancy (Davis-Floyd & Sargent; 1997; Landsman, 2009; Strong, 2000). However, Strong argues there is little evidence for such a claim. Although these mothers believed
in the power of prenatal care, they did not see the preterm birth as a failure of biomedicine. They blamed themselves. Landsman described maternal blame as mothers being held responsible for birth outcomes because pregnancy and birth are subject to individual control. This is a common theme in the literature, as mothers report guilt and blame for their preterm deliveries (Hall, 2005; Garel et al., 2006; Landsman; Lee et al., 2009). Feelings of self-blame and guilt were influential as mothers reframed their motherhood in such a way to maximize their control to help their infants.

**Conditions**

Multiple studies were reviewed that described aspects of the NICU experience. Infant constitution or related concepts were not identified in any previous studies. Holditch-Davis and Miles (2000) interviewed 31 mothers and found that infant illness, treatment, and appearance were stressful aspects of the experience for mothers, but did not state how mothers viewed the infants. In the current study, words mothers used to describe the infants have significant meaning. They chose words such as feisty, strong, superstar, trooper, active, fighter, strong-willed, stubborn, and alert. These words represent the maternal view of the baby, which is having an internal will to live and thrive. Although some mothers described the babies as physically tiny in the beginning, they all used descriptors that indicated the strength of the baby. This belief of strength in the baby is important as the mothers will act upon and create meaning based on this belief.

Maternal attributes of love and dedication have also been reported in the literature (Charchuk & Simpson, 2003; Ricciardelli, 2010). In the current study, these attributes were not conditional upon infant outcomes. This finding was also described in the
literature. Ricciardelli wrote an unintentional ethnography after her own experience with preterm birth. She wrote expressly about unconditional love and potential complications not making a life unworthy of living. She described a deep desire that her babies would live and a need for the medical providers to “do anything they could” to ensure survival (p. 2). Charchuk and Simpson described dedication as loyalty as “an unreserved commitment, no matter what the situation” (p. 40).

The condition unexpected course and/or roller coaster has been well documented in the literature. As noted in this study, even mothers who experience prolonged preterm labor are often not prepared to face the overwhelming environment and unpredictable course of the NICU. Parents were constantly uncertain about their child’s survival (Cohen, 1993; Santacroce, 2003; Hall, 2005; Jackson, Ternestedt, & Schollin, 2003). In the current study, uncertainty about survival shifted to uncertainty about what unexpected occurrence or complication may occur next. There was also outcome uncertainty, but this was less focused upon. Layne (1996) discussed the concepts of uncertainty, course, and roller coaster in her first-person ethnography. Uncertainty is described as dominating the course; furthermore, the course is descriptive of the infant’s journey within the NICU with no implications about the direction. The course is likely to resemble a roller coaster. She states that the roller coaster does not only describe changes in the baby’s physical condition, but the swirling maternal emotions.

Maternal emotional responses to the NICU experience were the focus of Obeidat and associates (2009) literature review of 14 qualitative studies. They found anxiety, powerlessness, depression, alienation, hopelessness, and uncertainty to be the common themes in their review. These feelings were similar to those reported by
mothers in other studies (Golish & Powell, 2003; Hall, 2005). These responses were also found in the current study; however, mothers also described positive emotions such as love, hope, happiness, and thankfulness. When Emotional Swirling (Figure 4-3) was shown to mothers in the current study during the second interview, many commented that they were glad to see positive emotions included in the figure. Most studies seem to focus on the negative aspects of becoming a mother in the NICU. Reid (2000) also described emotional dichotomy, such as anxiousness and pleasure; however, she also focused upon negative feelings related to infant discomfort. Feelings of disbelief, anger, guilt, hope, and loyalty were described by Charchuk and Simpson (2003). The emotional response of mothers affects the processes and strategies used to manage this overwhelming situation.

**Process and Strategies**

Learning to mother described the processes of gathering, interpreting, and making sense of information. This information came from many sources, including the baby. Several research studies were identified that addressed information seeking. DeRouck and Leys (2011) published an article about information behavior of parents in the NICU and conducted interviews only with neonatologists and head nurses. Interestingly, they did not include any parents. Brazy and associates (2001) conducted interviews with parents and found that information seeking shifted from a passive to a more active approach. The type of information needed by parents shifted throughout the NICU stay. Parents used multiple information sources. These types of information-seeking behaviors were also seen in the current study. Physicians, nurses, family, internet, other mothers, and the infant were all viewed as potential sources of information. Mothers received and sought out information from the sources. Nurses were one
source of information and support. Kowalski and associates (2006) and Mok and Foon (2006) found that nurses were integral to parental communication and support. Communication was used as a method of support. This finding was consistent in the current study, as mothers described information received from the nurses in the form of support and translation of the physician message. Dickerson (2006) described women’s use of the internet and found that in a new health situation, women will seek information via the internet. Mothers in this study used the internet to verify or clarify physician explanations, as well as to seek out positive stories of former preemies. Mothers also looked to the babies for cues to how they were progressing. Loo and associates (2003) described teaching mothers to read their infants physiologic and behavioral cues as a way to decrease maternal stress. In the current study, this interpretation seemed a natural progression of becoming the mother.

The type of information seeking behaviors identified in this study informed the mothers’ strategies to reframe motherhood into a positive experience. Mothers sought information that allowed them to redefine their hopes in the most positive way. Hope as defined in Amendolia (2010) is a “basic human response essential for and associated with life meaning and quality of life” (p. 140). The role of hope in the NICU has been described in several articles (Charchuk & Simpson, 2003; Higginson, 2007; Kluge, 2006; Steinberg, 2006). Hope is not a stagnant process, but adaptable to context. Hope and loyalty have been described as the keys to parenting in the NICU (Charchuk & Simpson). Hope is described as “not dependent on health status” (Charchuk & Simpson, p. 42). Loyalty is defined as “unreserved commitment, no matter what the situation” (Charchuk & Simpson, p. 40). Furthermore, hope is described as action
driven, so mothers will act in ways that support their hope. Mothers in the current study often described their connection with physicians and nurses who supported their hope. They described evolving hope that changed with circumstances, which is the essence of redefining hope. Hope had a very clear role in helping mothers persevere in a situation in which they have little choice. Hope helped mothers reframe motherhood in a way that maximized their power.

**Consequences**

Lee and associates (2009) conducted a grounded theory study in Taiwan in which they described a new lived reality after their preterm infants were admitted to the NICU. They further described barriers to parenting and support systems utilized by the mothers. The concept of a new reality is consistent with findings of acknowledging a new uncertain trajectory in the current study as the shift in expectations occurs. Reframing motherhood adds a new dimension to the knowledge regarding the preterm birth and NICU experience in that it expressly studies meaning the mother develops in the context of preterm birth and IVH. Although there are many studies describing aspects of the preterm birth experience, there is a relative absence of studies that include specific complications. It is essential to understand the meaning mothers attribute to the experience as their actions will be based on this meaning. Layne (1996) states the research has not focused upon the knowledge or meaning-making practices of parents. Reframing motherhood explains how meaning is made within the NICU experience. This process can be examined as a transition into motherhood in an unexpected way.
Transitions

Reframing motherhood is a time of great transition even if the mother already has children. Mercer (2010) says that “transition into motherhood is a major developmental life event” (p. 94). Preterm entry into motherhood is very different than anticipated. The conditions that affect transitions have been described as the meanings, expectations, knowledge level, environment, and level of planning (Hattar-Pollara, 2010). All of these conditions are affected by preterm birth. Mothers are unsure of the meaning this will have for themselves or their babies. They have to create or develop meaning of the situation which is described in this study as reframing motherhood. This is an unexpected transition in that the timing and events surrounding the transitions are different than anticipated. They transition into a highly medicalized and stressful environment, which is also unexpected (Hall, 2005; Gavey, 2007; Shin & White-Traut, 2010). Their level of knowledge has to rapidly increase to understand all that is happening. This is a great source of stress (Holditch-Davis & Miles, 2000). Lastly, the level of planning is not congruent with expectations. These mothers thought they would be pregnant for another 12 to 16 weeks. During this time, there is a great deal of planning and adjustment to prepare for the transition into motherhood (Hattar-Pollara). Preterm birth causes mothers to transition into motherhood “off time,” which is a source of stress (Hattar-Pollara, p. 90).

Transitions have been described as developing a new self-concept that requires restructuring goals, behaviors, and responsibilities, and strategies are needed to accomplish this (Mercer, 2010). The strategies of living in the moment, reconstructing expectations, and redefining hope were described in this study. Mothers used these strategies to help them reframe motherhood in a manner that was consistent with the
new context. Mercer has described the transition into motherhood as maternal role attainment, which she believes is affected by perception of the birth experience, early separation of mother and baby, perception of the baby, health status, and social stress. Mothers who experience preterm births likely perceive their birth experience as negative (Golish & Powell, 2003; Hall, 2005). Mothers in this study largely described their births as stressful, unanticipated experiences. Although all infants in this study had many complications related to preterm birth, mothers overwhelming perceived the infants as strong.

Shin and White-Traut (2010) studied transition into motherhood in the NICU and found that the transition was a time-dependent process in which mothers experience psycho-emotional swirling, and hovered at the edge of motherhood. As a consequence, mothers needed to develop meaning related to family and life. Furthermore, they identified five attributes they described as needing to be alleviated for a positive transition. These included negative meaning, uncertainty, social prejudice, separation from the infant, and NICU environment. The current study described becoming a mother to a preterm infant who had an IVH focused on the strategies used to develop meaning. Although this is believed to be a time-dependent process, distinct phases were not identified, as in previous studies of motherhood in the NICU.

Wrbsky (2000) described meaning as a cognitive interpretation that symbolizes reality. Shin and White-Traut (2010) believed that negative meaning development should be avoided for a positive transition into motherhood. Mothers in the current study relied heavily upon hope to reframe motherhood in a positive manner. They created their reality based on multiple sources of information that were gathered,
interpreted, and subsequently used to make meaning. Ultimately, reframing motherhood meant that mothers acknowledged an uncertain life trajectory, but they retained power to influence outcomes. Shin and White-Traut identified uncertainty as needing to be alleviated; however, this may not be possible due to the inaccuracy of prediction in the preterm infant with IVH. Mothers in the current study managed uncertainty by focusing on the possibility of positive outcomes. Social prejudice was also identified as needing to be eliminated (Shin & White-Traut). This was described in the current study as maternal blame. They guilt and blame associated with preterm delivery is well documented (Hall, 2005; Landsman, 2009). Although mothers voiced that there was nothing they could do differently, they still felt responsible for their child being born preterm. Separation and environmental factors affected transition in mothers in the current study as described by Shin and White-Traut. Mothers were able to negotiate these barriers so that they did not prevent mothering; however, all mothers described looking forward to the transition home so they could fully embrace mothering the baby.

**Maternal NICU Experiences**

Multiple studies have described differing aspects of becoming a mother in the NICU. One literature review and one meta-synthesis were identified that described maternal experiences in the NICU (Cleveland, 2008; Aagaard & Hall, 2008). Due to differing inclusion criteria, each synthesis included some overlap, but each included studies that were not represented in the others. The literature review included 14 qualitative studies and the metasynthesis reported 60 qualitative and quantitative studies were included although, upon review, there were multiple publications from the
same studies. The majority qualitative studies were included in the initial literature review. Additional studies identified will be described individually.

Cleveland (2010) focused her literature review on needs of parents in the NICU. She found that parents reported needs for information, being close to the infant, protecting the infant, being perceived positively by the staff, and having a good relationship with the nurses. Emotional support, empowerment, supportive policies, and parent education helped meet these needs. Although maternal needs were not expressly addressed in the current study, the relationship with nurses was a common theme. Mothers described how the nurses provided emotional support and helped to foster hope. They were also a source of translation of information provided by the physicians. One mother described nurses as “the baby’s life-line.” Primary nursing was particularly important to mothers. Primary nurses would care for the baby anytime they worked. Several of the families had multiple primary nurses, so the baby was almost always cared for by staff familiar with their care. This was noted often by mothers as a positive experience because mothers had a high level of trust in these nurses.

In Aagaard and Hall’s meta-synthesis, multiple aspects of the NICU experience were described. Maternal-infant relationship, maternal development, neonatal environment, caregiving strategies, and mother-relationship were described. They found that mothering a preterm infant in the NICU was a developmental process that relied upon closeness to the infant and a warm mother-nurse relationship. Mothers in the current study also reported the need to be close to their babies, as well as the importance of the nursing relationship.
Most studies found regarding maternal experiences in the NICU identified phases mothers go through to ultimately become the mother. Fenwick, Barclay, and Schmeid (2008) conducted a grounded theory study in Australia in which they identified phases in which women learned to mother. Early in the NICU experience, mothers just existed, followed by striving to be the baby’s mother, then trying to establish competence, and, lastly, learning and playing the game. Jackson and associates (2003) also described the phases into motherhood as a time-dependent process form alienation to familiarity. Nuutila and Salantera (2006) described diagnostic, learning, and coping phases. Hurst (2001a & 2001b) described actions mothers took to safeguard their infants, including vigilant watching over, and strategies mothers used to meet their needs, such as information gathering, and incorporating to evaluate potential dangers. Holditch-Davis and Miles (2000) described sources of stress associated with experiences in the NICU. These were related to pre-existing factors, perinatal experiences, infant condition, infant outcomes, loss of role, and healthcare providers. Understanding these findings and theories on transition into motherhood helps to understand how maternal transition is affected by preterm birth. However, there remains a lack of data related to what these differences meant to the mothers who experienced preterm birth. The findings in this study add to this body of literature by focusing on maternal meaning.

Limitations

Grounded theory relies upon the researcher being the tool through which data is gathered and interpreted. The researcher can affect the data through assumptions he/she brings into the study. I have extensive experience working with families whose children were born preterm and are dealing with long-term issues related to IVH. In order to limit these assumptions from influencing the data analysis, I used memo writing
as a technique to make these assumptions visible. This was done prior to beginning interviews and throughout the process. I also worked closely with a multidisciplinary qualitative data group, as previously described, to ensure that findings were remaining grounded in the data.

Another possible way that the researcher can affect the data is through data gathering techniques. Interviewing skills are crucial to this process. In terms of research, I am a novice interviewer. After listening to the interviews, I recognized there were topics that could have been further explicated in interviews by asking follow-up probes which could have enriched the data further. Theory developed is dependent on the data collected; therefore, rich data is crucial to fully expand concepts and their linkages. Grounded theory is utilized for theory development. This requires one to think and write conceptually, a skill developed over time. Inexperienced researchers may struggle to arise from a more descriptive to conceptual level.

Data collection in grounded theory produces large volumes of data which must be carefully analyzed in order to understand at a conceptual level processes at work and what they mean. This is dependent on choosing a perspective that gives the most explanatory power to the situation. Researcher inexperience may affect the ability to analyze, organize, and present the findings from the participant perspective on a conceptual level rather than merely describe them. Researcher inexperience in this study was tempered by working with a data analysis group with experienced methodologists.

Study sample size in this study may be viewed as a weakness. Twelve mothers participated in this study resulting in a total of 21 interviews. This resulted in over 700
pages and over 200,000 words of transcribed interview data, excluding data from field notes or memos. Although the sample size may appear small, there was a tremendous amount of data gathered and analyzed. The sample consisted of mothers with diverse education and income levels, as well as marital status and number of children (Table 4-1). The babies had both mild and severe IVH. Diversity among participants allowed for greater comparison and development of an explanatory model that included multiple perspectives. It may be noted that race and/or ethnicity is not included in the demographic table. This was an intentional decision by the researcher not to include this on the demographic data collection form (Appendix H). Race and/or ethnicity are culturally constructed categories commonly used in health research (Gravlee & Sweet, 2008). However, the argument has been made that “race and ethnicity are seldom defined or justified as inclusion for study variables” (Gravlee & Sweet, p. 29). As previously reported in the literature review, there is significant variance in the rates of preterm births among ethnic and/or racial groups living within the United States, with African-Americans being most affected (Behrman & Butler, 2007). The cause of this variance remains unclear. There is evidence that stress related to educational level and socioeconomic status may significantly affect preterm birth. Therefore, these demographics were included. One could argue that the participants could self-identify their race or ethnicity rather than choose a predetermined category; however, it would still be unclear how this could be interpreted in this study.

Reframing motherhood in the context of prematurity and IVH is intended to represent a specific population. Without further study, it is not possible to know if this model would be applicable to other populations or contexts. Mothers whose babies did
not have IVH were not included in this study; therefore, comparisons with mothers whose babies do not have IVH could not be made. This limits conclusions about how IVH changes the experience. However, this was the first study that examined mothers of infants with IVH, so I felt that it was important to understand the experience prior to making further comparisons.

**Future Research**

Preterm birth continues to be a complex situation with few answers. It is important to understand how mothers deal with this situation. Explanatory models, and therefore actions, will change as experience and context changes. Recommendations for future research include following families over time to understand how the experience of mothering a preterm infant with IVH evolves. This would demonstrate how understanding and meaning change over time. It would also provide understanding about how mothers deal with long-term consequences of preterm birth. Studies of outcomes of extreme preterm infants have been inconsistent, demonstrating a wide range of possible outcomes. (Boyce, Smith, & Cato, 1999; D'Angio et al., 2002; Behrman & Butler, 2003; Baron et al., 2009; Brouwer et al., 2008; Vassilyadi et al., 2003). It is hypothesized that reframing motherhood will be an ongoing process as circumstances evolve.

In order to understand how IVH influences the preterm birth experience for mothers, a comparison would need to be made between mothers whose babies have IVH and those who do not. Mothers of gestational age-matched infants with and without IVH could be interviewed. This would allow for a better direct comparison. If there are significant differences found, then supportive interventions could be developed based upon the findings.
The provider perspective was not addressed in this study. Interviews of providers would further understanding of this diagnosis from their perspective. Provider beliefs affect care and information dissemination, so this is an important component of the maternal experience. Mothers provided insight on how they interpreted provider beliefs. Knowing how providers are interpreting maternal beliefs and actions would improve overall understanding.

Fathers were not included in the current student. This is in no way intended to diminish the importance of the paternal role. Future studies should examine paternal perspectives and how they are developed. It is important to understand the influence of fathers in preterm birth complicated by IVH.

Lastly, research needs to continue related to the cause, treatment, and outcome of IVH. The level of uncertainty is so high because there is a great deal of ambiguity related to these areas. Mothers and their babies face a very uncertain future when dealing with this complication. Mothers wanted answers to questions that are currently unknowable. Increasing knowledge in these areas will support mothers by providing these answers.

**Implications for Practice**

There are many studies in the literature that describe the parental experience of having an infant in an NICU. However, none of these studies has addressed how a diagnosis such as intraventricular hemorrhage influences this experience. There are several areas in which knowledge gained in this study could be applied to practice.

First is to understand that mothers are going through a process of reframing their motherhood to be congruent with their new life circumstances. They are developing an explanatory model to make meaning of these events; it is an intense time of information
gathering, interpretation, and incorporation. There are specific strategies mothers are using to accomplish this. They are redefining hopes, reconstructing expectations, and living in the moment. Nurses need to understand this process so they can help support mothers do this in a way that focuses on maintaining hope while supporting expectation reconstruction that is congruent with the circumstance. Mothers are very aware of the high level of uncertainty regarding future outcomes so they are choosing to focus on the positive aspects of the experience. Mothers are choosing to focus on today because looking long-term is very overwhelming. There must be a balance between helping to develop expectations while not solely focusing on the future. Long-term outcomes of the children will be declared over many years. This will be a journey for mothers and expectations will likely continue to be reconstructed and hopes redefined.

It is important for providers to understand maternal beliefs regarding IVH. This is one complication among many and is not the immediate focus of mothers. A very important finding in this study is the invisibility of IVH. Mothers do not have infant cues to help them understand this complication. They are told there is bleeding in the brain, but the infant has not shown any outward signs of a problem. Head ultrasound images can be used to provide evidence of this complication. Secondly, as head ultrasound imaging is followed to determine resolution of the blood, mothers are interpreting this finding as resolution of the problem. Mothers need to be told that as the blood resolves, the possibility of sequelae such as hydrocephalus diminishes; however, damage caused by IVH remains. Uncertainty related to outcome of this damage is of utmost importance. Since there are no clear answers, mothers choose to focus on positive
possibilities which help to them to maintain hope. This is, again, very important to maintain, as it helps the mothers continue to face their uncertain future.

Although relationships with nurses were not the focus of this study, mothers all spoke of the importance of their relationship with nurses. Neonatal intensive care nurses were a primary means of support and information for mothers. It is important for nurses to understand the emotional swirling (especially the grief, guilt and blame) that mothers are experiencing. This is an area where nurses can provide support. Also, mothers tended to recall more information given by nurses, which may have been because they had more conversations with nurses, they were more comfortable or, perhaps, the information was provided in a more understandable way. Regardless of the reasons, nurses should be cognizant of the fact mothers are gathering information and information from nurses seems to be remembered. Therefore, nurses must ensure that they are providing the most accurate information possible. Neonatal intensive care nurses may consider journal clubs as a way to stay up-to-date on new research findings. Many mothers recounted anecdotal stories that nurses had told them, usually with an underlying message of hope. These mothers found support in the stories. Providing information in this more informal manner may also help mothers retain and understand it. Topics such as the importance early intervention could be approached in this manner. Many mothers struggled to recall information given to them early in this experience, which is consistent with previous research (Kowalski et al., 2006). It is unclear if mothers were not given the information or if they were so overwhelmed that they did not retain it. Recognizing that topics may need to be revisited over and over to support maternal understanding is important.
When healthcare providers feel that they have given mothers information, but they are not “getting it,” it should be revisited, as mothers may have misinterpretations of information or may not recall information they were given early in the NICU course. Mothers receive large volumes of information that is confusing, overwhelming, and often conflicting. They are interpreting many types of information to understand what is happening. However, once this has been done, then it is essential for providers to understand that mothers develop meaning and act upon it in a way that helps them to deal with a situation in which they have no control. They are developing meaning from their perspective, which is very different from the provider perspective. Mothers are in a situation in which they have little to no control. The babies have been born and have fought for their lives. They are alive and there are no decisions to be made. So mothers have no alternative but to reframe their motherhood in a way that allows them to deal with the situation. They need to have hope and remain strong. Providers need to understand that they may simply be misreading cues from the mother regarding her understanding. If providers are looking for tears and sadness from mothers when they have given what they deem to be bad news, they may not understand the maternal reaction. Mothers in this study were clear that they felt the need to stay strong for their infants. They felt if they broke down or were sad that the infants would sense negativity and this may negatively affect them. Mothers also needed to remain strong in order to face the uncertainty of the future. Understanding maternal needs is essential to providing family centered care.

Family centered care is an approach to care that utilizes partnering with families to provide care that is congruent with family beliefs and values (Gooding, Cooper, Blain,
Franck, Howse, & Berns, 2010). This approach is advocated within the NICU, but in order for it to be utilized, providers must understand family beliefs. Utilizing the findings in this study, providers can understand the overall process that mothers are using to develop their beliefs about the situation. However, to understand beliefs on an individual level, eliciting the maternal explanatory model as described by Kleinman (1988) is recommended. This will allow providers to understand how mothers are thinking about preterm birth and its complications such as IVH. Utilizing this method, misconceptions can be identified and providers can work with families to facilitate understanding. However, when there are differing perspectives, the maternal belief system should be respected and providers should work to provide care that is congruent and supportive of the family.

The experience of preterm birth and its subsequent complications is overwhelming for mothers. Providers must not become immune to this fact as they face their daily work with families. Mothers are struggling to develop understanding and meaning. Providers can be an enormous source of knowledge and support, but they must understand and respect strategies mothers are utilizing to help them deal with a situation in which they have no choices.

**Conclusion**

In conclusion, this study highlighted the process that 12 mothers utilized to reframe motherhood in the context of preterm birth complicated with IVH. The explanatory framework, Reframing Motherhood, explains the intense process mothers go through and factors affecting the process to develop meaning of their situation. Findings describe the actions, interactions, and strategies that are utilized, as well as consequences of this process.
Mothers have been thrust into a situation in which they have little control or experience. They must create meaning of this new life circumstance. They are overwhelmed by all the information they must gather, interpret, and incorporate into their life. They are reliant on hope to get them through this intense situation. Mothers are forced to face a situation fraught with uncertainty every day. They were never asked if they wanted to ride this roller coaster. They have very few choices, so they must find a way to manage these circumstances. Hope is heavily relied upon to provide the mothers with the strength to face the situation. This hope has been redefined within a new set of circumstances. These mothers are at the beginning of a long journey through motherhood. It is not the motherhood they expected, but they continue to hope that it will be a good motherhood. They need ongoing strength to face the uncertainty. Hope will give them the strength they need. Healthcare providers can be pivotal in helping transform hope of mothers.

This study adds to the current body of knowledge related to the maternal experience of having a preterm infant with IVH by addressing the meaning mothers attribute to the experience as this will affect their actions and reactions to the situation. As previously described, studies have addressed issues of role attainment and becoming a mother by describing the stages mothers go through during their NICU experience. However, these do not address maternal meaning. Based on the principles of SI and explanatory models, actions can only be understood through understanding the meaning. By utilizing a grounded theory methodology, the contextual and conditional aspects of this process were also elucidated. Obediat and associates (2009) specifically recommend the use of “a grounded theory approach to understand
the process parents go through during the time their infant is in the NICU” (p. 27).

Knowledge gained from this study can be combined with other research findings to enhance the overall understanding of this phenomenon. Kowalski and associates (2006) found that parents desired more information about IVH and neurological damage. Utilizing this information along with information about strategies that mothers use to help them develop meaning may help providers structure information in a way most beneficial to mothers. This study was a necessary first step in understanding how mothers perceive IVH and what it means for their lives.
APPENDIX A
IRB APPROVAL LETTERS

UF
Institutional Review Board
UNIVERSITY of FLORIDA

Health Science Center / Jacksonville
College of Medicine
Institutional Review Board
FWA00005790

580 West Eighth Street
Tower II, 9th Floor, Suite 9015
Jacksonville, Fl 32209
(904) 244-9478
(fax) (904) 244-9035

MEMORANDUM

DATE: February 9, 2011

TO: Teresa MacGregor,

FROM: Sheila Heim, CIP
Coordinator, Institutional Review Board for
Alan Halperin, MD
Chair, Institutional Review Board

SUBJECT: Expedited Review of UFJ 2011-4

TITLE: Understanding Maternal Expectations and Needs Following Neonatal Intraventricular Hemorrhage

Your request for approval of the above study under the classification of expedited was reviewed in the IRB office and as IRB Chair I am pleased to inform you that your study was approved on 2/8/2011 under the following expedited category(s):

1. Clinical studies of drugs and devices only when:
   a. An investigational new drug application (IND) or investigational device exemption (IDE) is not required, and there is no significant increase in risk or decrease in acceptability of risk, or
   b. The device is cleared or approved for marketing and is being used in accordance with its labeling.

2. Collection of blood samples by finger, heel, or ear stick, or venipuncture no more than twice weekly as follows:
   a. From healthy non-pregnant adults weighing at least 110 pounds, in amounts less than 550 ml per 8 weeks.
   b. From other adults and children, considering the health and habitus of the subjects, in amounts less than 50 ml or 3 ml per kg (whichever is less) per 8 weeks.

3. Prospective collection of biological specimens for research purposes by noninvasive means. Examples:
   a. Hair and nail clippings (non-disfiguring).
   b. Deciduous teeth at exfoliation or indicated extraction
   c. Permanent teeth excreta at indicated extraction
   d. Excreta and external secretions including sweat
   e. Uncumulated saliva
   f. Placenta removed at delivery
   g. Amniotic fluid at the time of rupture of the membrane prior to or during labor
   h. Supra- and sub-gingival dental plaque during routine prophylactic scaling
   i. Mucosal and skin cells by buccal scraping or swab, skin swab, or mouth washings.
   j. Sputum after saline mist nebulization

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An Equal Opportunity Institution
SUBJECT: Expedited Review of UFJ 2011-4

TITLE: Understanding Maternal Expectations and Needs Following Neonatal Intraventricular Hemorrhage

_4_ Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Examples:
   a. Physical sensors that do not involve input of significant amounts of energy or invasion of privacy.
   b. Weighing or testing sensory acuity.
   d. Moderate exercise, muscular strength testing, body composition assessment and flexibility testing where appropriate for age, weight and health.

_5_ Research involving materials (data, documents, records, specimens) that have been or will be collected solely for non-research purposes (such as medical treatment or diagnosis).

_6_ Collection of data from voice, video, digital, or image recordings made for research purposes.

☑_7_ Research on individual or group characteristics or behavior (such as studies of perception, cognition, motivation, identity, language, communication, cultural beliefs and practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

You must inform the Board of any modifications or changes to this research (protocol or consent changes) since they could affect its expedited status.

Please note the category of informed consent listed below that has been approved for this study.

☑_ You have been granted approval to conduct this study using the enclosed stamped, IRB-approved consent form. This consent must be photocopied and used when enrolling subjects into this project.

OR

_____ You have been granted a waiver of documentation of informed consent, in lieu of a verbal consent.

OR

_____ You have been granted a waiver of informed consent.

Your protocol is approved until 1/25/2012 at which time you will need to submit a regular continuing review report in order to continue the study. This study has been approved for enrollment of 30 subjects. If you find the need to increase this number, please submit a Revision to the IRB office immediately.

Thank you for informing the Board of your proposal.
MEMORANDUM

TO: Teresa MacGregor, MSN, ARNP

FROM: Michael Joyce, MD, PhD

DATE: July 6, 2011

RE: Expedited Review – Initial Approval

The Institutional Review Committee (IRC) of Baptist Medical Center (BMC) met on June 29, 2011, and the new protocol listed below was reviewed and approved via expedited review for a period of one year:

#11-39, Rehabilitation Nursing Foundation, "Understanding Maternal Expectations and Needs Following Neonatal Intraventricular Hemorrhage".

- Protocol Submission Checklist;
- Financial Disclosure Form;
- Submission Letter;
- Consent document, version date 10 June 2011;
- Protocol, no version date;
- Sample Interview Questions;
- Invitation to Participate

Enclosed is the stamped consent with the approval and expiration dates needed to enroll patients. The anniversary date for this study is June 28, 2012. At that time, please submit a report of your experiences with this protocol.

Should you have any questions, please contact the IRC office. The BMC IRC meets the requirements in 21 CFR 56 (Rev.), 45 CFR 46 (Rev.) and ICH (E6) GCP guidelines. Good luck with this endeavor.
September 9, 2010

Teresa MacGregor, MSN RN ARNP-BC
7919 Vivera Ct.
Jacksonville, FL 32244

Ms. MacGregor,

The Rehabilitation Nursing Foundation Research Fund Committee is pleased to inform you that your proposal titled Understanding Maternal Expectations & Needs Following Neonatal Hemorrhage has been accepted for the RNF New Investigator Grant Award. The amount of this grant is for $10,000.

Thank you for submitting your proposal for the panel’s review. An agreement will be sent to you/your institution following the conference this Fall and funding will begin January 2011.

Sincerely,

Susan Floutsakos
Manager
Informed Consent to Participate in Research
and Authorization for Collection, Use, and
Disclosure of Protected Health Information

You are being asked to take part in a research study. This form provides you with information
about the study and seeks your authorization for the collection, use and disclosure of your
protected health information necessary for the study. The Principal Investigator (the person in
charge of this research) or a representative of the Principal Investigator will also describe this study
to you and answer all of your questions. Before you decide whether or not to take part, read the
information below and ask questions about anything you do not understand. Your participation is
entirely voluntary. If you choose not to take part in this study, you will not be penalized or lose any
benefits to which you would otherwise be entitled.

1. Name of Study Participant

______________________________

2. Title of Research Study

Understanding Maternal Expectations and Needs Following Neonatal Intraventricular Hemorrhage

3. Principal Investigator Name, Address, and Telephone Number(s)

Teresa MacGregor, MSN, ARNP  UF Doctoral Student

IRB version date: 12/13/2010
PI version date: 1/20/2011

Pt. Initials ______

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4. Source of Funding or Other Material Support

Rehabilitation Nurses Foundation

5. What is the purpose of this research study?

The purpose of this study is to gain better understanding of mothers' expectations and needs following the diagnosis of neonatal intraventricular hemorrhage or "bleeding in the brain".

6. What will be done if you take part in this research study?

You will be asked to participate in 2 interviews conducted by Teresa MacGregor. The first interview will be conducted before your infant is discharged from the hospital. The second interview will be conducted between one and six months of your infant being discharged home from the hospital.

6a. What procedures would be done as part of your normal clinical care (even if you did not take part in this research)?

Your infant's clinical care will be determined by his/her physician. This study does not involve your or your infant's clinical care.

6b. What procedures will be done only because you are taking part in this research study?

There will not be any procedures performed on you or your infant because you are participating in this study.

If you have any questions now or at any time during the study, you may contact the Principal Investigator or contact person listed on the front page of this form.

7. If you choose to take part in this study, how long will you be expected to take part in the Research?

You are being asked to participate in two interviews. The time between interviews will be dependent on your infant's length of stay in the hospital. The second interview will be conducted between one and six months after your infant's discharge home from the hospital.

8. How many people are expected to take part in this research?

20

9. What are the possible discomforts and risks?

There are no known risks associated with the study. Participating in the interview may produce emotional discomfort.
This study may include risks that are unknown at this time.

Taking part in more than one research study or project may further increase the risks to you. If you are currently enrolled or have recently taken part in another research study, you must tell the person reviewing this consent form with you.

Throughout the study, the researchers will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator or contact person listed on the front page of this form.

10. What are the possible benefits to you?

You may or may not personally benefit from taking part in this study. Participants could potentially feel better from talking about things that may bother them about their infant.

11. What are the possible benefits to others?

In the future, knowledge learned from this study may be used to help mothers understand and cope with the diagnosis of neonatal intraventricular hemorrhage.

12. If you choose to take part in this research study, will it cost you anything?

There is no cost associated with this study.

13. Will you receive compensation for taking part in this research study?

Participants will receive a $20 gift card at the completion of each interview.

If you are paid for taking part in this study, your name and social security number will be reported to the appropriate University of Florida employees for purposes of making and recording the payment. You are responsible for paying income taxes on payments provided by the study. If the payments total $600 or more, the University of Florida must report the amount that you receive to the Internal Revenue Service (IRS).

14. What if you are injured because of the study?

If you are injured as a direct result of your participation in this study, only professional psychological care that you receive from a University of Florida ("UF") psychologist at the University of Florida Health Science Center/Jacksonville ("UFHSC-J"), Baptist Medical Center ("BMC") or Wolfson Children’s Hospital ("WCH") will be provided without charge. However, care from a non-UF psychologist and hospital care and expenses including that which is provided by UFHSC-J, BMC, WCH or any other hospital, will have to be paid by you or your insurance provider. You will be responsible for any deductible, co-insurance, or co-payments. Some insurance
companies may not cover costs associated with research studies. Please contact your insurance company for additional information.

No additional compensation is routinely offered.

The Principal Investigator and others involved in this study may be University of Florida employees. As employees of the University, they are protected under state law, which limits financial recovery for negligence.

Please contact Teresa MacGregor 904-228-2096 if you experience an injury or have questions about any discomforts that you experience while participating in this study.

15. What other options or treatments are available if you do not want to be in this study?

You have the option not to take part in the study.

16. Can you withdraw from this research study?

You are free to stop taking part in this research study at any time without penalty and without losing any benefits to which you are entitled.

If you decide to stop taking part in this research study for any reason, you should contact Teresa MacGregor: [redacted]

If you have any questions regarding your rights as a research participant, you may call the Institutional Review Board (IRB) office: [redacted]

17. If you withdraw from this study, can information about you still be used and/or collected?

If you stop taking part in this study, no new information will be collected about you. However, information that was already collected may still be used and shared with others if the researchers have relied on it to complete and protect the validity of the research.

18. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons:

- You do not qualify to be in the study, because you do not meet the study requirements.
- The investigator decides that continuing in the study would be harmful to you.
- You are unable to keep appointments.
- The study is cancelled by the Sponsor, and/or other administrative reasons.

IRB version date: 12/13/2010
PI version date: 1/5/2011
Pt. Initials: [redacted]
19. If you agree to take part in this research study, the Principal Investigator will create, collect, and use private information about you and your health. Once this information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected about you and your health (called protected health information), will be stored in locked filing cabinets or in computers with security passwords. Data will be stored on a secure UF server. Only certain people have the legal right to review these research records, and they will protect the secrecy (confidentiality) of these records as much as the law allows. These people include researchers for this study, certain University of Florida officials involved in this research, and the Institutional Review Board (IRB; an IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research). Otherwise, your research records will not be released without your permission unless required by law or a court order.

If you take part in this research study, the researchers will collect, use and share your protected health information with others. Items 20 – 29 below describe how this information will be collected, used, and shared.

20. If you agree to take part in this research study, what protected health information about your infant may be collected, used, and shared with others?

Your infant’s protected health information may be collected, used, and shared with others to determine if you can take part in the study, and then as part of your participation in the study. This information can be gathered from you or your infant’s past, current, or future health or study records, from procedures such as physical examination, x-rays, blood or urine tests, or from other procedures or tests. More specifically, the following information may be collected, used, and shared with others:

- Results of your infant’s medical tests such as x-ray, MRI, head ultrasound
- Information you provide in interviews
- Questionnaire

If you agree to be in this research study, it is possible that some of the information collected might be copied into a ‘limited data set’ to be used for other research purposes. If so, the limited data set may only include information that does not directly identify you. For example, the limited data set cannot include your name, address, telephone number, social security number, or any other photographs, numbers, codes, or etc. that link you or your infant to the information in the limited data set. If used, limited data sets have legal agreements to protect your identity and confidentiality and privacy.
21. For what study-related purposes will your protected health information be collected, used, and shared with others?

Your infant’s protected health information may be collected, used, and shared with others to make sure you are eligible to take part, to carry out, and to evaluate the results of the research study. More specifically, your infant’s protected health information may be collected, used, and shared with others for the following study-related purpose(s):

To determine if you can take part in the study.

Once this information is collected, it becomes part of the research record for this study.

22. Who will be allowed to collect, use, and share with others your infant’s protected health information?

Your infant’s protected health information may be collected, used, and shared with others by:

- the study principal investigator, Teresa MacGregor and the research staff associated with this project
- other professionals at the University of Florida or Shands Jacksonville that provide study-related treatment or procedures
- the University of Florida Institutional Review Board (IRB), an IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research.

23. Once collected or used, with whom may your infant’s protected health information be shared?

Your infant’s protected health information may be shared with:

- the study sponsor, Rehabilitation Nursing Foundation
- United States and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections

The study data sent by the researchers to the study sponsor will not include your or your infant’s name, address, social security number, or other information that directly identifies you or your infant. Instead, the researchers assign a code number to the study data and may use your or your infant’s initials. Some study data sent to the sponsor may contain information that could be used (maybe in combination with other information) to identify you or your infant (for example, your date of birth). If you have questions about the specific health information that will be sent to the study sponsor, you should ask the study investigator(s).
Otherwise your research records will not be released without your permission unless required by law or court order. It is possible that once this information is shared with authorized persons, it could be shared by the persons or agencies who receive it and it would no longer be protected by the federal medical privacy law.

24. If you agree to participate in this research, how long will your protected health information be collected, used, and shared with others?

Until the end of the study.

25. Why are you being asked to authorize the collection, use and sharing of your protected health information?

Under a new Federal Law, researchers cannot collect, use, or share any of your protected health information for research unless you allow them to by signing this consent and authorization.

26. Are you required to sign this consent and authorization and allow the researchers to collect, use and disclose (give) to others of your protected health information?

No, and your refusal to sign will not affect your treatment, payment, enrollment, or eligibility for any benefits outside this research study. However, you cannot participate in this research unless you allow the collection, use, and sharing of your protected health information by signing this consent/authorization.

27. Can you review or copy your protected health information collected, used, or shared with others under this authorization?

You have the right to review and copy your protected health information. However, you may not be allowed to do so until after the study is finished.

28. Is there a risk that your protected health information could be given to others beyond your authorization?

Yes. There is a risk that information received by authorized persons could be shared with others beyond your authorization and not covered by the law.

29. Can you revoke (cancel) your authorization for collection, use, and sharing of your protected health information?

Yes. You can revoke your authorization at any time before, during, or after your participation in the research. If you revoke, no new information will be collected about you. However, information that was already collected may still be used and shared with others if the researchers have relied on it to complete and protect the validity of the research. You can revoke this authorization by giving a written request with your signature on it to the Principal Investigator.
30. How will the researcher(s) benefit from your being in this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator or other researchers may benefit if the results of this study are presented at scientific meetings or published in scientific journals.
31. Signatures

As a representative of this study, I have explained to the participant or the participant’s legally authorized representative the purpose, the procedures, the possible benefits, and the risks of this research study, the alternatives to being in the study, and how the participant’s protected health information will be collected, used, and shared with others.

Signature of Person Obtaining Consent and Authorization  Date

You have been informed about this study’s purpose, procedures, possible benefits, and risks; the alternatives to being in the study, and how your protected health information will be collected, used, and shared with others. You will receive a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. You hereby authorize the collection, use, and sharing of your protected health information as described in sections 20 – 29 above. By signing this form, you are not waiving any of your legal rights.

Signature of Person Consenting and Authorizing  Date

Approved [02/08/2011] Expires [01/25/2012]
PARENT/CAREGIVER INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

This form explains the research. This form also lists the information about you that will be obtained during the study, how it will be used, and with whom it will be shared. You should understand the study well before you agree to be in it. The people in charge of the study will answer your questions about it at any time. We encourage you to ask questions and take the opportunity to discuss the study with anybody you think can help you make this decision.

1. WHAT IS THE TITLE OF THE STUDY?

Understanding Maternal Expectations and Needs Following Neonatal Intraventricular Hemorrhage

2. WHO IS IN CHARGE OF THE STUDY AT BAPTIST MEDICAL CENTER?

   Principal Investigator: Teresa MacGregor, MSN, ARNP

   Co-Investigators: None

   Research Coordinator: None

   Contact Information: NA

3. WHO SHOULD RESEARCH PARTICIPANTS CONTACT ABOUT THEIR RIGHTS?

   Chairman, Baptist Medical Center Institutional Review Committee

4. WHAT IS THE PURPOSE OF THE STUDY?

   The purpose of this study is gain better understanding of mothers' perception and expectations following the diagnosis intraventricular hemorrhage.

5. WHO IS SPONSORING OR PAYING FOR THE STUDY?

   Rehabilitation Nursing Foundation.

6. WILL THE INVESTIGATOR'S MAKE MONEY FROM THIS STUDY? (See Financial Conflict of Interest information)

Version date: 6/10/2011
No

7. WHO CAN BE IN THE STUDY?

Mothers whose infant is admitted to the neonatal intensive care unit and has been diagnosed with bleeding in the brain (intraventricular hemorrhage) may participate in the study.

8. HOW MANY OTHER PEOPLE WILL BE IN THE STUDY?

Approximately 20

9. HOW LONG WILL PARTICIPATION IN THE STUDY LAST?

Two interviews will be conducted approximately six apart.

10. WHAT ARE THE RESEARCH PROCEDURES?

You will be asked to participate in 2 interviews conducted by Teresa MacGregor MSN, ARNP. The first interview will be conducted before your infant is discharged from the hospital. The second interview will be conducted within six months of your infant being discharged home from the hospital.

11. WHAT ARE POSSIBLE RISKS OF BEING IN THIS STUDY?

There are no known risks associated with the study. Participating in the interview may produce emotional discomfort.

12. WHAT ARE POSSIBLE BENEFITS OF BEING IN THIS STUDY?

You may or may not personally benefit from taking part in this study.

Participants could potentially experience an emotional benefit by voicing their concerns related to their infant.

13. WHAT HAPPENS IF A PROBLEM OR INJURY RESULTS FROM THE RESEARCH PROCEDURES?
Please contact the Principal Investigator Teresa MacGregor if you experience any emotional discomfort while participating in this study. She will provide you with contact information for support groups and counseling.

14. IS BEING IN THE STUDY VOLUNTARY?

Yes

15. WHAT ARE OTHER CHOICES BESIDES BEING IN THE STUDY?

You may choose not to participate in the study.

16. CAN THE RESEARCHERS REMOVE SOMEONE FROM THE STUDY?

You may be withdrawn from the study without your consent for the following reasons:

- You do not qualify to be in the study, because you do not meet the study requirements.
- The investigator decides that continuing in the study would be harmful to you.
- You are unable to keep appointments
- The study is cancelled by the Sponsor, and/or other administrative reasons.

17. WHAT ARE THE COSTS OF BEING IN THIS STUDY?

None.

18. WILL PEOPLE BE PAID FOR BEING IN THIS STUDY?

Participants will receive a $20 gift card at the completion of each interview.

19. WILL PEOPLE IN THE STUDY BE TOLD OF ANY NEW INFORMATION THAT MIGHT AFFECT THEIR WILLINGNESS TO STAY IN THE STUDY?

Yes.

20. WHAT INFORMATION ABOUT ME WILL BE USED OR DISCLOSED?
Health information about your child will be collected and will include identifying information such as name, date of birth, and ethnicity. The security of the paper records will be maintained in a locked file cabinet and electronic records secured with password protection. Once the information is stored electronically, your child's information will be key coded to a study number and identifying information stripped. A key to the code will be stored separately. Information from all the subject's enrolled in this study will be combined and individual patients will not be singled out. The results of this study may eventually be presented at meetings or in print. However, your identity will not be disclosed in those presentations. The results of this project will be shared with Baptist Health physicians and administrators. Information may be exchanged between medical investigators, but patient confidentiality will be maintained.

All information will be kept confidential. Your child’s identity will be protected as much as the law permits. The Sponsor will receive information from this study.

Your research records and this signed consent form can be inspected by:

- Study Management Program or representative
- the U.S. Department of Health and Human Services
- Baptist Medical Center Institutional Review Committee

The privacy of your information cannot be guaranteed after it is disclosed. Research study materials that include your child’s health information will be stored securely for up to a 10 year period and then will be destroyed. This will not affect his or her usual medical record.

21. SIGNATURES

I am making a decision whether or not to participate in this study. I have read, or had read to me in a language that I understand, all of the above. I have asked questions and received answers about things I did not understand. I willingly give my consent for my child’s participation in this study.

My signature indicates that:

I give the researchers permission to disclose (release) information that identifies my child, and health information about my child, for this research study. I understand that:

- I can cancel this authorization/consent. The use and/or disclosure (release) of information will stop after the cancellation is received. Information that is used or disclosed before a cancellation may still be used.
- My information may be disclosed again by the person or entity who receives it. If this happens, Federal or state law may not protect my information.
- I have the right to refuse to sign this authorization.
- If I refuse to sign this authorization I will not be allowed to be in this research study.
- I have the right, in general, to ask the PI to tell me who has received my PHI (Protected Health Information). However, the list would not include information that was released for research studies with signed consents.
- I will receive a signed and dated copy of this authorization.
- By signing this informed consent document, I am not waiving any of my legal rights.

Parent / Legal Representative Initials: ____________

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<table>
<thead>
<tr>
<th>Name of Participant (Print)</th>
<th>Signature of Participant</th>
<th>Date</th>
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<td></td>
<td>(18 years of age or older)</td>
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<tr>
<th>Name of Parent/Legal Representative</th>
<th>Signature of Parent Legal/Representative</th>
<th>Date</th>
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</table>

Description of Legal Representative's Authority to act on behalf of the Participant (for example: "Parent" "Legal Guardian")

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<tr>
<th>Name of Person Administering Consent</th>
<th>Signature of Person Administering Consent</th>
<th>Date</th>
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I, the undersigned, certify that to the best of my knowledge, the subject/parent/legal representative signing this consent had the study fully and carefully explained. He/she clearly understands the nature, risks and benefits of participation in this project.

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<th>Signature of Investigator/Designee</th>
<th>Date</th>
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Parent / Legal Representative Initials: ____________
APPENDIX D
COUNSELING SERVICES

1. Mental Health Resource Center  904-642-9100
2. Jewish Family Services  904-448-1933
3. Children’s Medical Services  904-360-7070
AN INVITATION FOR STUDY PARTICIPATION...

Purpose:
This research is being conducted to learn about mothers’ expectations and needs when their premature baby has been diagnosed with an intraventricular hemorrhage or “bleeding in the brain”

Study Investigator:
Teresa MacGregor is conducting this study as part of the Doctoral Nursing Program at the University of Florida. She has 16 years of NICU and pediatric nursing experience.

Requirements:
You will be contacted by Teresa MacGregor to discuss your participation in this study. If you agree to participate, you will be asked to sign a form giving Teresa MacGregor permission to conduct a recorded interview with you. Then an interview time and place will be scheduled while your baby is in the hospital. A second interview will be scheduled between one and six months of your baby going home.

Thank you:
You will receive a $20 gift card at the completion of each interview for your participation.

Please contact the study investigator with any questions:
Teresa MacGregor MSN, ARNP

Mother’s copy
Version date: 1/6/2011
I, ______________________, understand that I am providing contact information so that Teresa MacGregor, University of Florida Doctoral Student, may contact me to discuss participating in a study about neonatal intraventricular hemorrhage "brain bleeding". I understand that signing this paper DOES NOT obligate me in any way to participate in this study.

____________________
Mother’s Signature

Mother’s Name:______________________________

Best Daytime Phone Number:______________________________

Best Evening Phone Number:______________________________

Email (Optional):__________________________________
APPENDIX F
INITIAL INTERVIEW GUIDE (INTERVIEW 1)

1. Tell me about the birth of your baby? (Probes: How long did you experience preterm labor before the baby’s birth? Why do you think you experienced preterm labor? Who talked with you about premature birth before you delivered?)

2. When did you learn your baby would have to come to the NICU?

3. What did you think when you heard your baby was going to be admitted to the NICU?

4. What has the experience of having your baby in the NICU been like for you?

5. How did you find out that your baby had bleeding in his/her brain? (Probes: Who talked with you about this? What questions did you have when you learned about it? Have the nurses/doctors answered your questions about your baby’s condition?)

6. What do you think caused the bleeding?

7. What do you think the term “IVH” (or “bleeding in the brain”) means for your baby?

8. What types of treatments do you think you baby will need?

9. What do you hope the results of the treatments will be?

10. How do you think that this illness (condition) will affect your baby? Your family?

11. What are your plans for taking your baby home?

12. What kind of help/assistance do you think your baby will need when you get home?

13. What do you fear most about IVH?
APPENDIX G
REVISED INTERVIEW GUIDE (INTERVIEW 1)

1. Tell me about your pregnancy and the time leading up to the birth of your baby?
   (Probes: How long did you experience preterm labor before the baby’s birth?
   Why do you think you experienced preterm labor? Who talked with you about
   premature birth before you delivered?)

2. When did you learn your baby would have to come to the NICU?

3. What did you think when you heard your baby was going to be admitted to the
   NICU?

4. Tell me about the day you came into the NICU for the first time.

5. What has the experience of having your baby in the NICU been like for you? How
   has this experience impacted your life?

6. What has the baby’s condition been since he has been born. Describe the
difficulties, complications, or setbacks that your baby has experienced. What
types of treatments has your baby needed?

7. How did you find out that your baby had bleeding in his/her brain?
   (Probes: Who talked with you about this? What questions did you have when you learned about
   it? Have the nurses/doctors answered your questions about your baby’s
   condition?)

8. What do you think caused the bleeding?

9. What do you think “IVH” (or “bleeding in the brain”) means for your baby?

10. What types of treatments do you think your baby will need? What do you hope
    the results of the treatments will be?

11. How do you think that this illness (condition) will affect your baby? Your family?
12. What do you think the staff believes about the effects of IVH? Are these in conflict with your own beliefs?

13. What are your plans for taking your baby home?

14. What kind of help/assistance do you think your baby will need when you get home?

15. When you think about your baby, what are your biggest hopes/fears?
APPENDIX H
DEMOGRAPHIC FORM

Understanding Maternal Expectations and Needs Following Neonatal Intraventricular
Demographic Information

1. Age of mother:____________________________________________

2. Marital status:
   □ Single
   □ Married
   □ Divorced

3. Mother’s education:
   □ Less than high school
   □ High school
   □ Some college
   □ 2 year college degree
   □ 4 year college degree
   □ Graduate School

4. Occupation:____________________________________________________________

5. Hours a week working out of the home:______________________________

6. Household income:
   □ Less than 25,000/yr
   □ 26,000-50,000/yr
   □ 51,000-75,000/yr
   □ 76,000-99,000/yr
   □ Greater than 100,000/yr

7. Total number of pregnancies:_________________________________________

8. Total number of living children and ages:______________________________

9. Number of pregnancy losses:_________________________________________

10. Infant gestational age in weeks:_____________________________________

11. Infant current age:_________________________________________________
APPENDIX I
SECOND INTERVIEW GUIDE (INTERVIEW 2)

1. What was the experience of having your baby in the NICU like for you?
2. What do you think caused your baby to have IVH?
3. What do you think the term “IVH” (or “bleeding in the brain”) means for your baby?
4. What types of treatments does your baby need? (Probes: Are these treatments different than what you previously expected?)
5. What do you hope the results of the treatments will be?
6. How do you think that this illness (condition) is affecting your baby? Your family?
7. What was it like to bring your baby home?
8. What kind of help/assistance does your baby will need?
9. What do you fear most about IVH?
Field Note 1.2

This interview was conducted in the neurosurgery office. It was conducted 7 months after the baby was discharged. The dad and daughter were present. This mom is struggling with depression and feels traumatized over the birth and the entire experience. Although, she is very thankful for all the providers that helped. She seems angry at her OB. Seems that it is actually harder to be home than in NICU where she is monitoring the baby. She lost support when her support group was over which has been very hard for her. She may feel less supported now that when she was in NICU.

She has a strong belief in the power of early steps to make a difference. But seems to have had trouble getting into the program. Another mother also spoke of difficulties with follow-up.
What do mothers perceive the implications of neonatal intraventricular hemorrhage to be for their preterm infant?

(a) How do mothers describe their understanding of the diagnosis?

(b) How do mothers develop their understanding of the diagnosis and the potential implications?
Diminishing Disability:

***Data analysis last week we discussed that Figure 3-Diminishing disability is a maternal belief system. This is informed by culture that says that biomedicine will continue to progress and has power to heal or transform. The commitment of the mother, the will/drive/or character of the infant, and biomedicine can influence or diminish disability. This allows some control in the situation. There are many complications or obstacles to overcome. Each of these will be the focus when they are occurring. IVH is more background. May come to the forefront if there is a complication such as hydrocephalus. Mothers can focus on other more pressing issues because this is a more long-term problem. The infant surviving has made him a miracle. He has a drive or will to beat the odds. The mother is committed to doing whatever it takes. Biomedicine offers therapies that have the power to influence outcome. By this time, the baby has overcome so much...through this triad he can continue to overcome and diminish disability. This belief drives the action. Do not have to deal with IVH today, but when the time comes there is some control over the situation. SI--we act upon things based on the meaning it has for us.

This may be the central dimension. This is the belief system that is driving the understanding of IVH. The mothers are on an altered trajectory, and there are many influences...but this triad is really the belief system.
APPENDIX M
MEMO TWO

Memo Interview 11

This interview was very enlightening. I asked the opening prompt about the mom's pregnancy and birth of the baby and the mother just started talking as though she knew all the themes that I have been working through. It was amazing as I could the model solidifying. This feels so much better than leaving the first interviews and having no idea what to make of the stories the moms were telling me. There was so much information with no clear indication how it was going to fit together. I think I have been reaching saturation during the last several interviews. The central themes seem to be "Survival to Going Home"--This is the total focus of the mom when the baby is in the NICU. Hope/Faith are central to this process--these are the primary strategies that the mom uses to get through the situation. Faith may be in the religious sense, but it is also faith in the baby's ability, faith in herself to "be there", and faith in medicine. The baby is a "fighter, miracle baby". He has beaten the odds. Mother has maternal blame related to the preterm birth. Now she has the power to influence the outcome of the baby through her vigilance. She has to "be there" for the baby. She will constantly observe for indications of something being wrong. "Is the baby acting like a normal baby". Delays are expected...worse (disabilities) are possible, but all this remains extremely uncertain. However, these outcome possibilities can be positively influenced through the mom observing, working with the baby, providing a good, loving environment, and managing biomedical care. This is how the mother is empowered. Up to this point, she has been powerless. There really have not been any decisions to be made. The baby is born into a system and the system does what it does...saves. "The system" seems to have a life of its own. Who controls it?? Assessment, test, interventions over and over. I specifically asked the mom if she was ever given any choices and she stated that she had not. However, if she was given a choice she would not have chosen differently. "Save the baby"--survival is the focus. At this time, it is all that matters. The future is uncertain and it can be dealt with tomorrow. Today I have to focus on the immediate problems and SURVIVAL. Biomedicine also has the ability to influence the outcome through assessing and providing therapies. IVH implications can be dealt with later. It is invisible so it doesn't have to be faced daily. The outcome is so uncertain and will not occur until a year or more later. Will deal with the problem if and when it happens. "Living day by day"--it's too overwhelming to look at the whole picture so choosing a face the immediate problems and not look into the future. --This is a strategy. Mothers are struggling to make meaning of the experience and meaning of IVH. Meaning of IVH is developed through medical communications (laying out possibilities, but uncertain), through maternal observations of the baby (take cues from the things the baby is doing...alert, growing, MAE, grasping finger, responding to voice), and internet. Focus is on "positive stories". This does not mean "perfect babies" it means survival, meeting some developmental milestones although maybe late. Some level of independence. This mom stated "I wanted a baby to love and I have that". She is hopeful for having limited problems, but will deal with what she has to deal with. The mothers state that no one can understand unless they have been through it. I think the same is likely the same for disabilities. The mothers certainly cannot understand how disability will affect their lives because they have not experienced it. IVH--invisible, resolves (mostly without treatment), effects may be lasting, but so uncertain, long-term issue so do not have to deal with it today.
"Altered trajectory"--this entire course is unexpected and the mother feels robbed of all the sociocultural expectations. The progress is no longer linear. This are happening randomly without warning.

There seems to be a maternal acceptance that this is my baby...no matter what happens this is my baby and I will do what I need to do. It doesn't seem that this is ambivalence or passiveness, but an acceptance that this is my baby whom I love. The mothers are dedicated and will be there for their babies doing whatever it takes to help. There is watchful waiting and observations where the mothers look for cues as to how the baby is doing. They are ready to intervene when necessary. The intervention is biomedicine...therapy. They will use the system to mitigate or diminish disability or maybe it is just alter the outcome. This is their power in a situation where they have been powerless. This seems to a belief system on which action is based, but it is also where mothers are learning to be advocates. Mothers of children with disabilities often need to advocate for the needs of their children. It starts very early with this process. The mothers need to watch and then act upon their observations.
Understanding the Maternal Perceptions of Neonatal Intraventricular Hemorrhage

Initial approach was to examine how a life changing diagnosis, IVH, was understood and acted upon by the mother. This shifted as it became evident that the crisis was preterm birth, not one specific diagnosis. Preterm birth results in an abrupt transition into motherhood that does not follow the expected linear course. The maternal focus initially is on infant survival “doing everything” to ensure the infant lives. Once survival seems likely the focus shifts to “going home” which is the expectation after delivery. The focus on going home begins months before discharge. Going home signifies a new beginning and leaving the tragedy of preterm behind. It is the expected course. **Fig 1** There are many problems to overcome prior to going home and IVH is one of these. **Fig 2** It is an invisible diagnosis that “resolves”. The effects are not immediately apparent and there is no treatment, just “watchful waiting”. The many other complications are more visible and require immediate treatment i.e. infections, respiratory distress, necrotizing enterocolitis. Mothers view complications as part of the roller coaster course of the NICU and deal with each one as they arise. They do not compartmentalize them according to overall effect once the initial danger as been alleviated. The effects of IVH are long-term; therefore, the immediate threat seems to be mitigated by the lack of evidence i.e. symptoms and treatment. Mothers believe their own diligence “doing whatever is needed...dedication”, the infant’s strong will, and the medical system (Early Intervention) can positively influence the long-term outcome of the infant. **Fig 3**—This is the maternal belief system that is likely driving the actions of the mother. I think that this is a reflection of a larger cultural belief system in individual power of the individual to influence the future and the power of biomedicine.

**Current focus/problem:**

How do the pieces fit together to develop the experience in it’s entirety?
Dimensions:

Central dimension: Mothering, Accelerated Mothering, Mothering in an altered trajectory...This situation is about becoming a mother of a preterm infant, but it is more than becoming a mother it is fulfilling this role in an unanticipated way. Fig 4

Context: Sociocultural beliefs—there is a right way to be pregnant and deliver...it is the mother’s responsibility to ensure a safe, healthy pregnancy and delivery by following culturally prescribed norms. There is an expected linear progress and preterm birth defies this progress. Biomedicine is powerful and has the capability of expanding the limits of viability. Views of disability and personhood. Is personhood believed to be diminished by disability.

Conditions Fig 5: Will change over the course of the experience: Physical conditions of the NICU, Emotional/Physical state of the mother as she recovers from pregnancy and delivery, mixed messages...common knowledge versus authoritative knowledge Fig 6, gestational age of infant, length of stay, IVH invisibility, watchful waiting, infant condition

Processes: Choosing hope—uncertainty of outcome allows the mother to remain hopeful...faith and love (maternal dedication) is also used of understand new trajectory. Fig 7

Consequence: Facing an uncertain future...parenting through the lens of “watchful waiting” may include disability on a continuum from mild->severe. Mothers want happiness and a level of independence for the child. The future may be able to be altered through the diminishing disability belief system. This is a period of transformation where the mother is taking on the role of advocate. This gives her power in a situation in which she has not had power.
**Belief that IVH may cause disability at some level, but uncertain how this will manifest. Providers can give information to help the unknown become known, but the uncertain cannot be made certain.**

**Implications:** Need to help invisible become visible. When should this be done? This can be facilitated by understanding the mothers core values/beliefs (explanatory model): 4 C’s

- **Cause:** How important is this? Is prematurity enough of an explanation of IVH? Some mothers create cause such as: he was so tiny that he banged his head around a lot when he was being born.

- **Course:** it resolves/dissolves, but damage remains—this is unseen

- **Consequence:** Uncertain...possible problems: learning disabilities, slower development, CP, hydrocephalus

- **Cure:** Early intervention, therapies, infant will, maternal diligence
THEMES

“The Mom”
Multiple Losses
Maternal Blame
Mom’s Mission—“Doing to Everything” until “Going Home”
Maternal Diligence
Staying Strong
Faith, Hope, & Love

“The Baby”
Fighter
Acting like a “normal baby”

“The NICU”
Riding the “roller coaster”
“It’s my first time”
Nurse-Mom relationship
Communication
Going home

“The Bleed”
Making the invisible visible
Watchful Waiting
Resolution
Acknowledging a complex and uncertain future
MATERNAL FOCUS - Fig: 1

Is the baby going to live?

Complications—Roller Coaster

Infant
Survival
Doing everything

Expectation

Going
Home

Represents survival
Start of real life
Being a mom
Doing what needs to be done
Facing an uncertain future
Preterm Birth Complications Fig 2

Crisis: Preterm Birth

- NEC: S/S Immediate Stop feeding Antibiotics Surgery
- Bradycardia: S/S Immediate Medication Oxygen Ventilator Antibiotics
- Retinopathy of Prematurity S/S Delayed Early Treatment
- Growth: S/S Immediate Increase feedings Increase calories
- Infections: S/S Immediate Bloodwork Antibiotics Ventilator
- Respiratory Distress: S/S Immediate Oxygen CPAP Ventilator

IVH: S/S Delayed Resolves

**This can be represent on the course on Fig. 4**
**This is a maternal belief system. Also, helps in maintaining hope and giving power to the mother. Outcome (disability) can be influenced. Mother has been powerless in the NICU, but now has the ability through her commitment and in her belief that biomedicine has the power to influence and that her infant is a fighter. I think that this fits together with Fig. 7**
Factors Influencing Understanding of IVH: Fig 5

Conditions

- Physical/Emotional Recovery
- Emotional Dichotomy
- Less
- Competing Messages
- Uncertainty
- High-tech Interventions
- Values-Beliefs Life, Death, Disability
- Invisibility Watchful Waiting
- Altered Trajectory

Maternal Understanding Of Neonatal IVH
"Infant is a fighter. He is going to be fine." Many premature babies are fine.

These conflicting messages also come from society. Information mom is seeking out. Only see the miracle stories online. Receive positive messages.

"Baby has grade IV intraventricular hemorrhage which is the worst. Your baby could have severe disabilities."
Processes: Fig 7
Using Faith, Hope, and Love to explain new life trajectory

Faith - Biomedicine
Higher power

Love - Maternal Dedication

Hope - Good future
Happiness
Independence

Facilitated by Uncertainty

PROCESS
Context

Biomedicine: Technology/Viability Limits_Sociocultural Beliefs

When women become a mother there is a social role expectation which is dependent upon cultural beliefs. Women engage in this social role prior to the birth of the baby as they move through their pregnancy and prepare for the birth of the baby. For some women, this may even begin prior to pregnancy as they adjust their lifestyle in accordance with planning to become pregnant. In the United States, the social role of motherhood requires women to care for their bodies to ensure the health of the baby. Caring for their bodies includes active participation in prenatal care and avoidance of potential toxins such as drugs and alcohol. Other factors which may have deleterious effects on the pregnancy such as stress should also be avoided. Mothers are keenly aware of these expectations during their pregnancy. There is a strong belief that individual mothers have control over their pregnancies and doing everything right results in a healthy baby (Landsman, 2009).

Becoming a mother to baby with IVH results in an unexpected motherhood for women.

Perspective: Changing expectations

Motherhood under construction: remodeling expectations

Reframing motherhood

Remodeling maternal expectations

Finding hope through expectation reconstruction

Mothers whose children are born preterm and experience IVH find themselves on an altered trajectory of mothering. This is very different from the anticipated course. They now must figure out how to navigate through this frightening time. The mothers have lost their expected cues as they are entering this social role. Their abdomens have not grown as expected. There was no baby shower or preparation of the nursery. Their families and friends are not celebrating the birth of their baby. They have entered in to motherhood earlier than projected in a highly uncertain situation in which they feel unprepared. The survival of the baby is in question and the surroundings are foreign. They are quickly interpreting many cues to help them make sense of what is happening. Cues are coming from the baby, healthcare providers, family, friends, and media. Mothers begin to reformulate their expectations as this interpretation occurs. The expectation of having a full-term healthy baby now changes to infant survival. “Save the baby” is the focus of this early time. Although, none of the mothers were given a choice regarding resuscitation, all stated that they wanted everything done to save the baby. Only one mother stated that she did not fear that her baby would not survive. Mothers were given probability statistics by healthcare providers related to infant morbidity and
mortality, but they were also told that individual prediction is virtually impossible. They deduced from this information that there was a high level of uncertainty regarding their infant's outcome. Because of this high level of outcome uncertainty, there was hope that their infant would not only survive, but the effects of the preterm birth could be minimal. The beliefs about the effects of preterm birth would change with the varying health status of the baby. The mothers understood that complications could have an effect on their baby in the future. IVH was viewed as a complication with a high level of uncertainty. They were told that it was very difficult to predict the long term effects; although, they were able to list the possibilities. However, at this time did not seem to incorporate this into their life because it was not a reality yet. IVH was described as resolving so there was nothing to worry about now. There was an acknowledgement that their children's lives may be difficult and this made the mothers feel sad. A good quality of life was described as having some level functional independence (although this was not clearly delineated), being happy, and being able to learn. The mothers were clear in their dedication to their children. This was not dependent on the outcome of the baby. The mothers would “be there” for the infants regardless of the impact of the prematurity or complications. Mothers believed in their ability to influence the future of the child. They believed that maternal dedication would result in a better outcome. The utilization of biomedicine was one pathway that mothers described as important to improving outcome. Specifically, rehabilitation through speech, occupational, and physical therapy were noted as influential. Following through with appointments with specialist was also noted as important to influencing the future.
Understanding Maternal Needs and Expectations Following Neonatal Intraventricular Hemorrhage

1. IVH likely to impact neurodevelopment which may affect physical and intellectual function throughout lifespan

- Diagnosis seems to be invisible . . . so how do you code for what is NOT being said???

2. After initial 3 interviews became clear that IVH was not central to the experience of mothering of preterm infant when asked, mothers were unable to verbalize the cause, treatment, or potential implications of IVH especially if the baby was still very young i.e. days-weeks

**Shift--The preterm birth/NICU experience will shape mothers’ thinking about their infant; thereby, affecting their actions and decision making....shift focus from the diagnosis and impact of IVH to the overall maternal experience of mothering a preterm infant. How is this experience shaped or affected by IVH?

- Does IVH affect the mothering experience?
- Is it invisible to the mothers?
- How do the mothers make meaning of the event and then the subsequent complications?

2. Trying to capture the maternal narrative to understand how IVH fits into this experience

1. How does maternal stress and feelings fit
   - This is really hard
   - I am really scared
   - I’m overwhelmed
   - I feel really stressed

Hope vs. Fear--remaining hopeful as a strategy...maybe to avoid fear?
Unknown vs. Uncertainty—are these the same concept or different

**seems unknown may be inexperienced and uncertainty is a known phenomena, but unsure of how it will turn out**

Unexpected jolt into mothering this infant (even if not a first time mother)

--Context--how this event occurred...realization baby will be born early and then the actual event and the interactions that occurred

P6:

--So they gave me the choice, they said, you can try and wait, and not have your baby, and then your liver’s gonna fail and you’re gonna have to have emergency liver surgery. And then you’re going to have to have a C-section, have your baby early, still. Or we can take your baby, save you the other surgery and, you know, take your chances with what happens. So we decided that since it was inevitable either way, that we would go ahead and just have her. So, then she was born. And she was very, very tiny, and you know, when they, when we were in the operating room, they were like, you really shouldn’t expect her to live with, you know—they said, if she is moving and, and, you know, struggling, then we’ll try and save her, but if she isn’t responsive then we’re not going to do anything. So, you know, so you’re advised. And I was like, no. No, we’re not going to have that.

--It was, it was very scary and it was hard to connect that with what I had felt inside me, you know. It was hard to look at her and know that’s my baby. She didn’t look like a baby. She looked like a little alien doll is what she looked like. She had no fat. Her skin was see-through. It was bright red and see-through. It was really scary. You know, her face was all taped up, cuz she had the, the jet ventilator, and you know, it’s vibrating her. You see her moving, you’re not allowed to touch her.

P2

They had—when he was delivered, because it was so quick, quick, the doc—they couldn’t, like, they really didn’t have, like, all their stuff, because they thought I was
They was telling me to stop pushing. I was, like, “I’m not pushing. The baby’s coming on its own,” so everything was, like, so quick, but I seen him. Then they had to rush and put him in a little, the little machine thing.

Need to fulfill mothering role—mothering tasks—seems central

• You have to earn being a mother
• Is the idea of MOTHERING the central dimension through which everything is filtered and interpreted???

P6

--You know, for the longest time I didn’t get to pick her up until she was 12 weeks old. At all. You know. I, I couldn’t change her diaper. I was told when I could touch her, or how I could touch her. You know, and as a mom, you want to take over those things. And I just felt so powerless and helpless. You know, being shoved out of the way for other people to take care of my child and, you know. I basically felt like I wasn’t her mom. And it was, you know, even now it’s really exciting to be standing in a room with no nurses over my shoulder saying ‘you can’t do that’ you know, don’t act that way, or whatever.

Interviewer: Right. So how does that make you feel when you know you have somebody kind of looking over you and, and telling you what to do?

Participant: I felt useless, you know. It’s like, well why am I here? You know, I can’t take care of her. I can’t provide the things that she needs, and that’s what a parent is supposed to do. You’re supposed to be able to feed them and change them and make them feel better, you know.

And, and like when she got bigger and she’s still on the vent and still on the vent, she started fighting it. And she’d rip her tube out and she would fuss, she would cry with her mouth open but no sound coming out, and it’s just, it’s so hard to watch her struggle and be in pain and be uncomfortable and I couldn’t do anything about it. I couldn’t even put my hand on her chest and say ‘there, there, baby, it’s okay!’
And you know, you, you feel, you just feel extraneous. And like you’re in the way, like when you come, you know, like the nurses are like, okay, it’s great that you’re here, cuz you’re her mom, but can you move, cuz we need to do stuff to her? You know, we need to give her these medicines that you don’t know what they’re for, and we need to do these tests on her that you won’t understand the results. And it’s, it’s hard to feel like that. You know, you don’t want to. You wanna be involved, but you don’t want to be in the way. So.

Interviewer: Did they share those things with you when you were—?

Participant: Yeah, you know, all of the nurses that we had were, were very friendly and you know, they took the time to explain ‘this is what we’re doing, this is what it’s for’ you know, but ultimately it’s them who, who does it. I am not trained in that. I can’t do it, you know? I can’t suction her if she needs it. And I can’t, you know, decide what milliliter feeding she needs today. It’s, it’s nice to be able to do those things now. To earn the privilege to be a parent. Cuz it, it is a privilege to actually be able to take care of her, you know?

1.
2.Interviewer: Wow. Wow, that’s very striking. To earn the privilege of being a parent.
3.
4.Participant: Yeah. We had to earn it, you know. I mean, we had to show them that we learned how to change a diaper. That we can be alone in a room with her and feed her, you know, and change her.
5.
6.Interviewer: What does that do to you? You know, inside, feeling like you’re having to earn someone else’s trust or permission—?
7.
8.Participant: It makes you feel, it makes you feel very inadequate, like you’re never doing it right, and like you’re never doing enough, you know? And like—
Invisible

• Diagnosis is invisible...no immediate treatment and connections to baby’s overall stability is difficult to make
• Sections are important for what is NOT being said

P6

9. Interviewer: What kind of complications did she have during—?
10.
11. Participant: Well, the first one that I remember was she got MRSA. She got MRSA. So instead of just wearing gowns, we had to also wear gloves. We couldn’t, so when we could start touching her, we still couldn’t touch her, because we had gloves on. So you know, our baby’s extent of human contact is gloved hands. And um, and she got, for a while she had the, the prematurity of the eyes, like they thought they were going to have to give her laser eye surgery. Um, she, she had chronic lung disease because she was on the vent so long, the vent was actually making her sick while keeping her alive. So, you know, they’re trying to wean her from it, but they can’t because she’s dependent on it, because it makes her sick, cuz it keeps putting fluid in her lungs.

12.

13. Um, she kept getting uh, stomach infections, like you know, inside her, where they’d have to stop feeding her because um, her stomach would just not digest things properly and milk would just sit there. And you know, just grow and grow and she wouldn’t poop. Or pee. And she would get so swollen. Like she would, for a while she looked like a balloon baby. And it wasn’t, you know, like cute fat and chub. It was like swolleness.

14. Um, and then she had bleeding on the brain and some, then she got a wound on her foot from the G-tube, cuz you know, she can’t eat, so that was obviously another complication, and they, they said, well round her due date, she should start to pick it up. And her due date came, and her due date went, and we’re still waiting, and for a while she took bottles
really good. And we’re like, she’s getting it! You know, she’s gonna come home soon! This is great! All of a sudden she stopped. She just wouldn’t take anything anymore. You’d put the bottle in her mouth and she’d choke and gag and act like you were trying to kill her.

15. And um, so that was when they decided to put the G-tube in, but then when they put the G-tube in, that got infected. And then where they had the IV in her foot, cuz they had to give her fluid and medicines through that, that got infected. And it’s still infected, so that was another thing. They had to put her on antibiotics like, I didn’t even know how many times she’s been on antibiotics. Dozens. You know, you’d always hear, she’s got MRSA again–

P4

They – they – they couldn’t give me a reason why his platelets used to be low. And then he had blood in his stool, abdominal problem. GI. His stomach specialist. So like with having – having a premature baby, it – it is some kind of complication that I feel like, in my heart, they’re gonna help. If – if they’re not having a stomach issue, they might do bradys, you know. It is some kind of complication. Your child just not gonna be perfect. He’s doing okay and all right.

1. Interviewer: Can you tell me about other complications he had?

3. Interviewee: Um, he had blood in his stool. That was another complication. The, um, disease specialist said that they believe in their heart that the antibiotics that he was on for a long time, like trichomycin and something else he was on for a long time, probably like ate up his good cells in his stomach. So that’s what probably caused the lower abdominal bleeding. Cuz when his dark blood – cuz his blood was like red, real, real red. Um, and when it’s real, real red, they said – they said that that means that it’s coming from the lower part, the lower abdominal. If it was coming from the up part, it would be dark red. Like, ah, all red. But, um, he’s – he’s okay. He – he – he–ah, to me,
my son is like a fighter to me in my heart. Because like the situations that he have been in, which is the bleeding—didn’t know—know like when the bleeding was like gonna stop. I used to say to myself like, "Oh, my God. Is the bleeding not gonna stop? Like it just didn’t stop. And I had to wait cuz like—I had to wait like 'til he got four pounds, six ounces to even—to even do a biopsy, something like that where you stick the scope up your butt with a—um, a—a camera. See, at first they was saying they wanted to do it blind without a camera. So basically they could be in his colon, but they probably could like pinch it and puncture it or something like that. They’d have to go up his colon. It—it was a lot of things. But he—he got it, ah, last Friday, and the results came out negative. Thank you, Jesus and God. Um, what else about him? Right. When he goes to the bathroom now—he had like a little small, like a little rash in his anus. But other than that he don’t—um, he don’t have no more complication. And, oh, another thing, when he first got off of his, um, cannula, he was breathin’ real fast like up to 100, 115, stuff like that. You know, you’re only really supposed to breathe like 40 percent.

IVH related issues:

P3 Interviewer: —with being a premature baby, which one of those things do you think will affect her growing and developing the most? Which one of those things do you worry about the most for her?

Participant: With her growing up and what will affect her? Her size. She's so small. My little sister, she's small and she's short. Well, like her size, she's gonna be littler than the other kids and probably learning. Her learning like talking.

Mostly I'm—I'm probably worried about her talking mostly. Like how like, you know, talking and being able to learn like
numbers, colors, and all that. That's something that she's gonna need extra help with and she's gonna like be extra attention with. That's—I know, she's probably gonna need that 'cause my little sister needed that so.

Information seeking

So, you know, they gave us all the information we asked for, but sometimes it’s hard to even know what to ask. You know? You, you’re like, well what information do I need to know about my baby? And you can’t even decide, cuz there’s so much. And then you, you think you figure out everything to ask about, and then you learn later that there was something that you missed, and then you feel like a bad parent because you didn’t know to ask. You didn’t know to go to them and say, well what about this number? Well what about this test? Well, did you do this? Did she have this service? You know, and it, it’s a learning experience, you know. And you get an education that you never wanted.

Well, a lot of times I am lucky enough to have an aunt in Wisconsin who works in the NICU. So I would, I would say, ‘they told me she has this, I don’t know what the heck that means’ and so then she would explain it to me. And she’d put it in, you know, mom-friendly terms.

Medical jargon--able to repeat, but difficulty integrating into understanding

I understood what was going on, I just don’t know how he—how he got this. You know what I’m saying? Like, what caused him to have brain bleeds, because I still don’t really understand still.
Well, he’s got a reservoir right now. [Laughter] and, and it’s funny, because some nurse was, like, “I don’t know anyone that, just, they don’t tap.” I mean, he, he finally got a tap on the head. But for a while, he didn’t, and, um, you know, they said that, you know, I could possibly, you know, every week or every other week do some taps. But then they’re, like, well, he’s just too young for a shunt or his skin’s too thin. I don’t know exactly too much about the shunt. But, um, so if he was to have that reservoir, I think that I’d have to come to the hospital or, you know, to the doctor’s for them to do it for, for me.

Faith

P1— but, you know, now I get to hold my son and just those little things I appreciate a lot more. Um, I definitely have a great faith in God now.
You know, and honestly, I think he’s a blessing just to be here. So I’m just thankful.
I’m altogether really thankful.

P4

Just seeing—you know, just looking in the incubator and you see your son or your daughter going through something. You’d be like I wish I could take their pain. I wish I could do something to, you know, relieve their pain, relieve whatever they’re—they’re going through. But I just feel like just praying to God—I know I talk about God and Jesus a lot. But I just feel like praying to God and Jesus is the only way I got out of it. I wouldn’t care who talkin’ to me—who—my mama. I don’t have no brothers or sisters. My grandmother, everybody else, even
when they used to try to talk to me, I used to tell them, y’all cannot tell me that y’all know how I feel, because y’all – y’all cannot possibly know how I feel cuz you never had a premature baby.

**Communication**

- **Nurse**—many references to “then the nurse explained to me”
- **Physician**

  P1

Yeah, he just had a real—they’re—but honestly, and I hate to say it, but the ones that have the accents I’ve seen, I think they’re, like, the most smartest for some reason [laughter], and I just wish that, you know. He was getting into details and I was just, like, “What?” Like, I needed somebody to help me, you know, understand. So I had the Internet to help me a lot better then. But, um, there was nurses after him and before him that helped me with it, and they was, like, well, you get to talk to the doctor and you’ll get to—you’ll have a better understanding. That wasn’t the case [laughter]. You know, like, there is one that I could actually understand him and he’s the doctor now of him. Referring to neurosurgeons
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BIOGRAPHICAL SKETCH

Teresa L. MacGregor began her career in nursing at 22 years of age after graduating summa cum laude from Jacksonville University. While at Jacksonville University she was honored with Laura Lee Wold award for clinical excellence and inducted into Sigma Theta Tau Nursing Honor Society. Upon entering nursing school, she knew that her career focus would be on children and upon graduation she pursued a pediatric nursing career. She began her nursing practice in the neonatal intensive care unit (NICU) where she loved caring for ill neonates and their families. After several years of practice, Teresa decided to pursue her master’s in nursing sciences degree at the University of Florida. She became a pediatric primary care nurse practitioner and practiced in this setting for about seven years when an unexpected opportunity presented itself. She was offered a position in pediatric neurosurgery. Always looking for an adventure, she decided to pursue this role. It was an amazing experience to utilize the experience she gained working in the NICU and in primary care in this new environment. Preterm neonates who developed posthemorrhagic hydrocephalus were a large portion of the neurosurgical population. Approximately one year after joining the neurosurgical team, Dr. Hector James encouraged her to pursue a doctorate degree in nursing. She was accepted into the doctoral program at the University of Florida, College of Nursing. Once in the program, she was encouraged to begin thinking about a research interest. She knew immediately that it would involve preterm infants and their mothers. Being a mother of five herself, she always felt a special bond with the mothers of the children for which she was caring. This bond made it very difficult to care for critically ill and dying children. This began to weigh deeply and take an emotional toll on her. She loved her practice, but knew she also needed to care for
herself. An opportunity to return to Jacksonville University to teach pediatric nursing arose. She immediately wanted to pursue this, but also loved practice. She was able to combine these roles in such a way that allowed her to do both. Currently, she is an Assistant Professor of Nursing at Jacksonville University while practicing part-time as a pediatric nurse practitioner in the Lucy Gooding Pediatric Neurosurgery Center. Through these roles, she has coauthored three manuscripts and presented at several professional meetings. She pursued her research interest in neonatal caregiving and was awarded a grant by the Rehabilitation Nurses Foundation. She hopes to pursue her research interests related to maternal caregiving and neonates in the future.